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Version: Version of Record

Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.21954/ou.ro.0000e28a>

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Oxford Regional Training Course in Clinical Psychology

An investigation of the relationship between perceived self-efficacy and
adherence to medication in people with HIV.

by

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July 1999

Dissertation submitted in part fulfillment of the requirements of the
Open University / British Psychological Society doctorate in
Clinical Psychology

Word Count: approximately 25000, including appendices

Abstract

New drug treatments have revolutionised the care of people with HIV, but they require exceptionally high levels of adherence. Research into the risk factors has been predominantly empirically rather than theoretically driven. Studies of adherence in other conditions have established the importance of perceived self-efficacy. Research studies exploring this relationship in HIV were conducted when the only available treatment was monotherapy, or with an exclusively female sample.

This study attempted to investigate the role of self-efficacy to adherence to antiretroviral medications in a UK sample of HIV positive people. It also aimed to explore the relationship between self-efficacy and depression. Finally, the relationship between self-efficacy and coping strategies was also considered. The study employed a cross-sectional design, with all participants completing a questionnaire at one time point.

Multiple regression analysis of the predictors of dose delays established that the two medication-specific self-efficacy measures accounted for 42.9% of the variance. No other predictors emerged from a stepwise regression.

Use of recreational drugs was the only predictor of dose omissions to emerge from a multiple regression. However, when drug use was controlled for, self-efficacy for adherence added a further 12.7% of the variance.

The findings of this study suggest that self-efficacy is related to adherence although the direction of causality remains to be established. Clearly, further research is needed to clarify the role of self-efficacy. Should it prove to be as significant as the results of this study imply, it is quickly and easily assessed and, moreover amenable to intervention.

Acknowledgements

At the start of this project, my self-efficacy for research was low, and it declined rapidly. That this has been completed at all is due to testament to the motivational power of social support, (chiefly Laura's), chocolate, and fear.

I would like to thank all the participants who took the time to complete the questionnaires, and the doctors who recruited them. Thanks are also due to Barbara Hedge, my supervisor, for help and perseverance when I was losing heart.

This could never have been completed without the generous, patient and clear advice of Paul Griffiths, whose help was invaluable.

I would also like to thank Myra Cooper for careful, quick, and constructive comments on my drafts.

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1. Introduction

1.1 General Introduction

“Keep a watch also on the faults of the patients, which often make them lie about the taking of things prescribed. For through not taking disagreeable drinks, purgative or other, they sometimes die.” (Hippocrates, On Decorum, cited in DiMatteo & DiNicola, 1982, p.9)

Concern about adherence to medical recommendations has a long, if not necessarily honourable history. Fortunately, there have been significant advances in the understanding of adherence, even if the gains are not commensurate with those in the medical treatments prescribed.

1.2 HIV and the Importance of Adherence

Scientific breakthroughs mean that even for conditions once thought fatal and incurable, effective treatments are available. Most recently, the development of Highly Active Antiretroviral Therapy (HAART), also called combination drug therapy, has revolutionised the care of people with HIV (Human Immunodeficiency Virus).

HIV

HIV suppresses the immune system leaving it vulnerable to opportunistic infections. The condition was first identified in the United States in 1981, but the virus itself was not isolated until 1983, allowing for the development of tests detecting the presence of antibodies to the virus. People testing positive for antibodies to HIV are termed “HIV

positive”, and those testing negative “HIV negative”. The virus invades particular cells in the immune system, CD4 cells. The number of CD4 cells per cubic mm of blood provides a rough estimate of the strength of the immune system. A count of less than 200 per cubic mm indicates that the body is vulnerable to opportunistic infections. These may affect the lungs, such as (pneumocystis carinii pneumonia, PCP), the digestive system, (cryptosporidiosis), the brain and the central nervous system, (toxoplasmosis) and the eyes, (cytomegalovirus). HIV is also associated with particular types of tumour, such as Kaposi’s sarcoma and lymphoma. HIV itself can enter the brain and cause a form of subcortical dementia. The presence of one of these conditions, (or a number of others) indicates a compromised immune system and is sufficient for a diagnosis of AIDS (Acquired Immune Deficiency Syndrome) to be made, although this term has fallen into disuse.

Means of Transmission

HIV is transmitted through body fluids, usually via sexual intercourse, by infected blood products, by the use of infected syringes during the injection of drugs, or by foetal transmission in utero.

Incidence

Worldwide, the spread of HIV has reached epidemic proportions, with HIV the leading cause of death in many African countries and several US cities, (Schoub, 1994). In the UK, over 24,000 people are known to be infected with the virus.

Treatment

Treatment trials have demonstrated that, in combination, the new drugs can prevent the virus from replicating over the long term, such that the amount of HIV contained in plasma is beneath detectable levels. Unfortunately, this does not mean the virus has been eradicated since it can survive in other parts of the body. The new combination drug therapies are considered largely responsible for a 48% decline in deaths from AIDS, and a 12% decrease in incidence last year, (Decock, 1998, cited in Hedge & Petrak, 1998). This has been referred to as the Lazarus effect, offering even those thought to be dying, a “second life” (Rabkin & Ferrando, 1997). Nonetheless, the new treatments have not provided miracle cures for everyone, and chief among the culprits are the development of drug resistance, and non-adherence to the drug regimens. Adherence to these requires considerable self-discipline. Patients are required to take up to thirty pills a day, at precise time intervals and often under strict nutritional conditions. For example, some pills must be refrigerated, some taken with food, some without, and some a couple of hours after eating. Incorporating such a regime into daily life is no mean feat, regardless of the degree of motivation. Some of these drugs also have side-effects including anaemia, nausea, diarrhoea, lipodystrophy, leukopenia, neutropenia and peripheral neuropathy.

The effects of non-adherence

The potential consequences of non-adherence are grave, both for the individual and for public health. When doses are missed, plasma drug concentrations fall below the level required to suppress viral replication. During these periods, the virus replicates up to

ten billion times a day, and mutates approximately once every ten thousand replications, (Chesney 1998, cited in Levine, 1998). Some of these mutations will have the potential to replicate in the presence of the antiretroviral drugs. The drugs may inhibit the non-mutated strain and leave a fertile environment for the drug resistant strain to flourish. Resistance to antiretroviral medication develops rapidly, within days of missed or subtherapeutic dosing, (Cinatl et al. 1994, Moutouh et al. 1996, cited in Mehta, Moore, & Graham, 1997, Ho, 1996, cited in Rabkin & Ferrando, 1997). Resistance to one class of drugs, protease inhibitors, can develop in a week, (Rabkin & Ferrando, 1997). Furthermore, resistance to one drug often entails resistance to other drugs in the same class, referred to as cross-resistance. This, therefore, may limit future treatment options dramatically.

The picture for those with HIV, then, is markedly different from those with other chronic conditions such as hypertension. The latter, if initially nonadherent, can recommence treatment at a later date without adverse consequences. That option is not available for those with HIV whose initial non-adherence has led to drug resistance. Subsequent treatment with the drug may also fail. This means that these patients may have only one opportunity with each drug. Adherence appears to be most crucial at the start of treatment, (Hall & Conway, 1997, cited in Birch, 1998, Lange, Reijers, & Weverling, 1998). Thus, it is most important when patients are unfamiliar with their medications, have not learned to integrate them into their routines, and are most likely to experience side-effects.

There appears to be a very direct relationship between adherence and the amount of virus in the body. One study, (Patterson, Swindells, Mohr, Brester, Vergis, Squier,

Wagener & Singh, 1999) used an electronic measuring device to plot the relationship between adherence at the start of treatment and the achievement of an undetectable viral load. They found that 81% of those maintaining adherence levels of over 95% had undetectable viral loads three months later. A 5% drop in adherence to 90-95% had a dramatic effect in terms of the proportion achieving this goal, 64%. By comparison, 50% of those managing 80-90% adherence had undetectable viral loads, and only 25% of those with 70-80% adherence. These rates plummet to just 6% for those whose adherence rates fall beneath the 70% threshold.

Other clinical markers, CD4 cell counts show a similar pattern, increasing by an average of 60 cells per cubic mm when adherence levels are greater than 95%. When adherence drops beneath 80%, CD4 counts decrease by 13 cells per cubic mm, (Chaisson, 1999).

95% adherence roughly translates as missing (or delaying) one dose a week. Should this happen twice a week, adherence drops to 90%.

In addition to the deleterious consequences for the patient, should viral transmission occur, the newly infected person(s) may carry the drug resistant strain. This raises the possibility of the development of multi drug resistant strains of HIV, (as happened with tuberculosis, Bloom et al. 1992, Sumartojo, 1993, cited in Ickovics & Meisler, 1997, Edlin et al. 1992, cited in Mehta et al.1997), which constitutes a major threat to public health.

1.3 Methodological Issues in HIV Adherence Research

Given this alarming situation, it is, perhaps, unsurprising that adherence has shot up the agenda of those working with HIV. Some of the pressure may be driven by the quest for sociodemographic, behavioural or personality variables predictive of non-adherence, so as to exclude these groups (such as injecting drug users) or individuals from treatment, (Eldred, Wu, Chaisson & Moore, 1997).

Unfortunately, the measurement of adherence is riven with methodological problems. The language itself remains contentious. Some authors use the term compliance but “adherence” is generally preferred because it avoids connotations of passive obedience. Labelling people “non compliant” sounds judgmental and implies any departure from medical recommendations is the patient’s responsibility. *“Non-compliance is the failure of the patient to fulfil the clinical prescription as it was intended by the practitioner”* (Hays & DiMatteo, 1987, p. 38). Adherence, similarly, has been variously defined, but the classic and widely quoted definition is Haynes’ *“the extent to which a person’s behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice”* (Haynes, 1979, cited in Epstein & Cluss, 1982, p.2-3). Adherence is a continuous not a dichotomous variable and most non-adherence is partial not total, so it seems more constructive to define the extent of adherence as precisely as possible, especially since particular levels of adherence are associated with differing clinical outcomes in HIV, (Patterson et al. 1999).

Within Health Psychology, adherence has been conventionally defined as taking more than 80% of one's medication. However, the adoption of such a definition within HIV is untenable for a number of reasons. Evaluation of adherence must also consider the threshold of therapy necessary for effectiveness, (Mehta et al. 1997). As yet, the specific quantities of each antiretroviral drug required to achieve viral suppression remains undetermined. However, recent research suggests, (Gulick, Mellors, Havlir et al. 1996, and Myers & Montaner, 1996, both cited in Mehta et al. 1997) that 90-100% of doses must be taken to suppress viral replication. Moreover, in the context of HIV, adherence entails more than the consumption of the requisite number of pills. The timing of doses, and the following of special dietary requirements, or the refrigeration of medications becomes equally important. Few drug assays exist for antiretroviral medications and they are not regarded as fail safe measures of adherence because of individual differences in the way the drugs are absorbed, metabolised, and excreted from the body, (Rainsford, 1999). Measuring adherence under these conditions presents methodological challenges, and many studies continue to use a predetermined standard of self-reported adherence and classify adherence as the percentage of people achieving this goal, (Broers, Morabia, Hirschel, 1994, Samet, Libman, Steger et al., 1992, Samuels, Hendrix, Hilton, Marantz, Sloan, & Small, 1990, cited in Eldred et al. 1997, Nakashima, Jones, Burgess, & Ward, 1998, Singh, Squier, Sivek, Wagener, Hong Nguyen, & Yu, 1996). Some researchers have chosen to rely on pill counts (Durvasula, Golin, & Stefaniak, 1998). Patients are required to bring their pill bottles to appointments and the number of pills remaining is subtracted from the total calculated. Unfortunately, this method takes no account of whether the pills were taken at the correct times.

Nonadherent patients, aware that their pills will be counted, may dispose of them before their appointment, a phenomenon known as pill dumping, (Ickowics & Meisler, 1997). Data collected using this method probably represents an overestimate of adherence (Rudd, Byyny, Zachary et al. 1989, and Cramer, Mattson, Prevey et al., 1989, cited in Ickowics & Meisler, 1997). In an effort to address this problem, some researchers, (Bangsberg et al. 1998, cited in Levine, 1998) have resorted to random unannounced pill counts. Technological advances have led to the design of pill bottles incorporating computer chips in their lids which record each date and time that the bottle is opened. However, as Epstein & Cluss (1982) point out, *“these methods do not actually measure medication use but rather measure use of the medication dispenser.”* Epstein & Cluss, 1982, p. 953). The Medication Event Monitoring System (MEMS) potentially provides more accurate information about whether and when medication is taken, (Ickowics & Meisler, 1997). Nevertheless, Ickowics & Meisler, (1997) caution against regarding it as a panacea. Such caution appears warranted, studies using this system, (Bangsberg et al., 1998, cited in Levine, 1998) cite 100% adherence according to MEMS, (as compared with 92% based on 3 day self-report, and 80% based on random pill counts). The authors commented that the full compliance recorded using the MEMS method probably reflected the fact that participants reported emptying out all the medications needed for the day at one time, thus defeating the object of accurate assessment of dosage times.

One disadvantage to both pill counts and electronic adherence measurement systems, rarely discussed in the literature, is the impact it may have on doctor patient relationships, in its implicit message that the patients' word cannot be trusted.

Ickowics & Meisler, (1997) remark that “*drug levels (e.g. serum or urine drug assays) and the use of inert biological markers (e.g. digoxin, phenobarbitone), are considered more objective measures of adherence, but are unavailable for some drugs and may be distorted by the ingestion of medication just prior to a medical visit, (i.e. “white coat compliance”)*” (Ickowics & Meisler, 1997, p. 389). In one study, (Eldred et al. 1998) incorporating urine testing to verify the self-report measure only 79% of patients reporting adherence had detectable drug levels.

A few studies take clinical markers, such as the achievement of an undetectable viral load as their outcome measures, (Graham, Beeler, Sension, & Renae, 1998). Clearly, adherence is important because of its demonstrated relationship with clinical outcomes. However, the two are not synonymous, and other factors mediate this relationship. One cannot assume that achievement of an undetectable viral load necessarily indicates adherence, nor that failure to achieve this goal is attributable to non-adherence.

Reviewing the methods used to assess adherence, Ley, (1988) concludes, “*patient report correlates reasonably well with other methods of assessment, the average correlation being about 0.47. The poorest method seems to be clinician’s estimate which has an average correlation of about 0.21 with other methods. Clinicians are also poor estimators of future compliance by their patients, (Sackett, 1979)*” (Ley, 1988, p. 281).

Writing in the Cambridge Handbook of Psychology, Health and Medicine, he points to the promise shown by standardised self-report questionnaire measures. However, it is fair to say that self-report measures may still overestimate adherence.

People may over report adherence because they forget episodes of non-adherence, they misunderstand medical advice and do not realise they are nonadherent, as well as because of deliberate deception.

It appears that the reporting of non-adherence is facilitated by the use of researchers independent from the clinicians responsible for medical care, and explicit that information will not be disclosed to these clinicians (Myers & Midence, 1998).

It has also been established that the more precise the question, the more accurate the response. Behaviour or medication specific adherence measures detect higher rates of non-adherence than general ones, (DiMatteo & DiNicola, 1982).

1.4 Adherence in Conditions Other than HIV

Studies of adherence in other conditions have established wide variation in adherence rates depending on the characteristics of the condition. It is worth noting that 6 - 20% of patients fail even to redeem their prescriptions, (Begg, 1984, Berradon et al. 1993, Rashid, 1982, and Waters, Gould, & Lunn, 1976, cited in Giuffrida & Torgerson, 1997). Adherence is conventionally defined as following the prescribed medical regimen 80% or more of the time, (Mehta et al. 1997). The highest rates of adherence (about 80%) are found in those with acute symptoms, (such as pain) who are required to follow short term (10 day) treatments, (DiMatteo, Hays, & Sherbourne, 1992, Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). These rates drop to about 50% in those with chronic conditions. Asymptomatic chronic conditions have the lowest rates of all, especially where lifestyle changes are involved. We also know that there is an inverse relationship between the number of medications prescribed and adherence, (Brand,

Smith & Brand, 1997, Clinite & Kabat, 1969, Davis & Eichhorn, 1963, Francis, Korsch & Morris, 1969, Hemminki, & Heikkila, 1975, all cited in DiMatteo & DiNicola, 1982).

The beneficial effects of adherence appear to be greater than those solely attributable to the drug. An article by Horwitz and Horwitz (1993) reports intriguing findings from a number of well controlled randomised double blind trials in which adherence is associated with positive clinical outcomes, even when the treatment is a placebo. These findings could not be accounted for by disease severity, stress, psychological characteristics, or high risk health behaviours, such as smoking.

Epstein & Cluss, (1982) speculate about the presence of a third variable to account for these effects. They suggest that adherent patients may lead more organised and healthy lifestyles, including exercise and healthier diet. Furthermore, they also argue that *“the act of adhering to a treatment regimen, which allows for a person to meet a well defined goal daily, may enhance feelings of well being and reduce psychological side-effects of a chronic disease”* (Epstein & Cluss, 1982, p.968). For well being, one could surely read self-efficacy.

Most of the research into adherence in chronic conditions has been conducted in populations with diabetes, hypertension, and cancer. These conditions typically require a protracted process of behavioural change including dietary control and the adoption and implementation of exercise programmes. Much of the medical management of the condition must therefore be ceded to the patient. This requires shared responsibility and collaboration between patient and practitioner.

One study, (Kavanagh, Gooley, & Wilson, 1993) examining the relationship between self-efficacy and adherence in diabetes, used multiple self-report and objective adherence measures. The use of a prospective design allowed them to include baseline measures of adherence. Their results demonstrated that self-efficacy was a significant predictor of adherence eight weeks later, even after the baseline levels of adherence were included in the regression analysis. The authors remark that *“self-efficacy judgements allow the person to assess a wide range of information they consider was relevant to their past adherence and to predict changes in the situation, in their skills or in their effort that may be related to their adherence in the future.”* (Kavanagh et al. 1993, p. 520).

Adherence researchers have tended to confine themselves to consideration of one of the following: patient characteristics, (sociodemographic variables, psychosocial factors such as, beliefs, coping, and social support), disease related variables (such as symptomatology), characteristics of the treatment regimen, (duration, complexity, side-effects), physician characteristics (job satisfaction), the patient / provider relationship (affective tone, communication style, overall satisfaction levels) features of the clinical setting, (transport, childcare, confidentiality). DiMatteo and his colleagues in California have devoted their energies to the mapping of this particular territory. Their development of measures for use across different clinical populations, has facilitated the evaluation of multivariate theoretical models. For the large-scale Medical Outcomes Study (MOS) (DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993) they designed the Adherence Determinants Questionnaire, (ADQ), general adherence questionnaire, and some measures of adherence to specific

treatment plan components, such as diet and exercise. These self-report measures were used alongside objective adherence measures, to investigate the stability of both general and specific adherence over a two year period with patients with heart disease, diabetes and hypertension. The correlation between general adherence at baseline and at the end of the study was .40. Specific adherence was more variable, with a test retest correlation of .32. The disease specific correlations were higher (diabetes specific .66, heart disease specific, .55, hypertension specific, .56, (DiMatteo et al. 1992).

Intriguingly, they reported that “*general adherence tended to improve over time, whereas adherence to certain specific behaviours (medication/ diet) became worse and adherence to exercise did not change.*” (DiMatteo, Sherbourne, Hays, Ordway, Kravitz, McGlyn, Kaplan, & Rogers, 1993, p. 99).

In this study, (DiMatteo, Sherbourne, Hays, Ordway, Kravitz, McGlyn, Kaplan, & Rogers, 1993, DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993, Sherbourne et al. 1992) the researchers assessed the relative weight of five factors associated with adherence in previous research, 1) past adherence levels, 2) health perception, 3) psychological factors such as coping style, 4) the presence of supports, (including social support) and the absence of barriers to carry out the prescribed behaviour, and 5) patient satisfaction with the practitioner patient relationship.

The strongest predictor of adherence two years later was the baseline adherence level. The next most powerful predictor of non-adherence was avoidance coping, (e.g. made self feel better by eating, smoking, or drinking). The authors also cite earlier work by Croog, Shapiro, & Levine, (1971, cited in Sherbourne et al. 1992) linking denial

coping with long term non-adherence. Interestingly, Sherbourne et al. (1992) did not find an association between active coping and adherence.

Health related distress, (frustration and despair) was also related to non-adherence which the authors speculate might be related to perceived inefficacy to improve their health.

Quality but not quantity of social support was positively related to adherence, and a clear relationship between age and adherence was found, with younger patients consistently less adherent.

Satisfaction with the financial and relationship aspects of medical care provision was also predictive of adherence. The relationship between patient and medical team has proved to be a crucial one. Early work in diabetes established the significant role this interaction plays in patient adherence. A high degree of adherence is required to manage this condition, and the procedures involved are aversive to most patients. Patients are fearful of criticism from medical staff. Amir, Rabin, & Galatzer (1990) argued that a range of specific cognitive and behavioural social skills are needed for patients to negotiate such interactions successfully. They hypothesised that assertiveness skills would be positively related to adherence. To test this, they designed a study which found some support for this proposition, although the direction of causality cannot be established.

A more thorough investigation has been conducted into the influence of physician characteristics as part of the MOS outcomes study referred to earlier, (DiMatteo, Sherbourne, Hays, Ordway, Kravitz, McGlyn, Kaplan, & Rogers, 1993). This found that the level of physician job satisfaction was associated with general

adherence two years later. Similarly, “*medication adherence was better among the patients of physicians who had busier practices that is who saw more patients per week*” (DiMatteo, Sherbourne, Hays, Ordway, Kravitz, McGlyn, Kaplan, & Rogers, 1993, p. 99) The authors reflect that this may be a function of their popularity, or, possibly that they met their patients more often in order to monitor their adherence, a practice widely assumed to improve it (Haynes et al., 1979, Meichenbaum & Turk, 1987). Certainly, the doctors in that study who made definite follow up appointments had higher rates of patient medication adherence. Another significant finding to emerge was that doctors reporting greater willingness to answer patients’ questions had patients who were more adherent to their exercise programmes. These results serve as salutary reminders of the degree of influence by healthcare staff on adherence.

Apart from the adverse effects on individual patients’ health, non-adherence incurs other costs. Ley, (1988) cites a 1979 estimate that non-adherence to the ten most commonly prescribed drugs would run to between \$400-800,000,000. Clearly, twenty years later, one might assume that the sum would be substantially greater.

1.5 Adherence in HIV

The new antiretroviral therapies require 90-100% adherence to maintain suppression of viral replication (Gulick et al., 1996, Myers, 1996, both cited in Mehta et al. 1997).

HIV is a chronic disease, which is commonly asymptomatic for up to ten years.

However, like many chronic conditions, its progression can be punctuated by episodes of symptomatic infection. It would seem plausible to expect adherence levels to fluctuate with greater adherence during symptomatic periods. Studies of patients with

HIV on AZT monotherapy found adherence rates of 60-88% with adherence defined as taking over 80% of medication, (Broers, 1994, Samet et al., 1992, Samuels et al. 1990, cited in Eldred et al. 1997). Despite the improved prognosis with combination therapies, adherence rates appear similar, (Gallant & Block, 1998). As yet, the most recent research is only available in abstract form, which makes the findings slightly more difficult to interpret. There is some evidence for longitudinal changes in adherence which appears adherence greatest at the start of treatment. Gallant and Block, (1988), found an inverse relationship between adherence and duration of treatment. Patients who had been taking their antiretroviral regimen between two months and a year reported an average of 6.2 days of “drug holidays”, days in which they stopped taking their medication completely. This compares with an average of 14.4 days “drug holiday” in those taking medication for over 25 months.

Patient Characteristics

Sociodemographic Variables

The relationship between sociodemographic variables and adherence in HIV has been well researched without any dramatic findings. In one prospective longitudinal study, age and adherence were unrelated, (Singh, Squier & Hayes, 1994, cited in Mehta et al. 1997). However, Klosinski & Brooks, (1997) found those under 34 were less adherent. This is particular cause for concern since most new diagnoses occur in this age group.

The evidence as regards sex differences is inconclusive as yet, although there is some evidence that men are less adherent than women, (Daniel, Rene & Daniels, 1994 cited in Mehta et al. 1997). Sexual orientation has also been investigated, although in

only one study. Using a rather crude measure of adherence/ non-adherence (whether participants reported taking their medications every day over the previous week), Klosinski & Brooks, (1997) found 71% of heterosexuals were adherent as compared with 62% of homosexual and 64% of bisexual participants.

More support has been found for a relationship between adherence and socioeconomic status, and related factors such as poor housing, (Daniel et al. 1994, cited in Mehta et al. 1997) homelessness, (Bangsburg, 1997 cited in Scherer, 1998) low income, (Klosinski & Brooks, 1977) and low educational level, (Daniel et al. 1994, cited in Mehta et al. 1997). Ickovics & Meisler, (1997) incorporate these in a more general category of “extreme adversity” which includes a number of other variables known to be related to adherence, unemployment, homelessness, incarceration, being the victim of a violent crime and hospitalisation for mental illness or substance abuse, (Broers, 1994, Morse et al. 1995, cited in Ickovics & Meisler, 1997). It is not hard to understand how, under such conditions, other issues may take priority.

The relationship between employment status and adherence is not as straightforward as it might at first appear. Unemployment is a risk factor, (Ickovics & Meisler, 1997), but other research, (Chesney, 1997) found working outside the home for pay was associated with non-adherence. This would suggest that there might be issues around fitting pill taking into a work schedule, and also that people might experience difficulties finding private space or taking their medications in public, (Eldred et al. 1997).

However, even when controlling for these variables, race remains a significant predictor of adherence. Ickovics & Meisler (1997) found the highest rates of adherence

(defined as having taken medications every day over the past week), amongst the Latino sample (72%). This compares with 61% of white participants, Only half the black sample met this adherence criteria.

Psychosocial / Behavioural Characteristics

One of the most well established risk factors for non-adherence is the presence of a psychiatric illness, especially depression, (Broers et al. 1994, cited in Ickovics & Meisler, 1997, Singh et al. 1996). This is the more significant given that between 17 and 30% of people with HIV are depressed, (Fernandez et al. 1989, cited in Mehta et al. 1997). Conversely those reporting a satisfactory emotional life also report higher rates of adherence, (Hollander, Agnoletto, Calvi, Cargnel, Carosi, Delia, Filippini, Mazzotta, Liberati, Spinasanti, Cazzullo, Clerici, & Martini, 1998).

Current substance use is another major vulnerability factor, (Hollander et al. 1998, Singh et al. 1996, and Broers et al. 1994, cited in Ickovics & Meisler, 1997). Similarly, Chesney & Ickovics, (1997) found an alcohol intake of over 17 drinks per month related to non-adherence. Substance use may be considered a coping strategy, (normally a maladaptive one when used long term). Other aspects of coping style have been found to be related to adherence, (Singh et al. 1996). Specifically, Singh et al. (1996) found adaptive coping was positively associated with adherence.

The evidence as regards social support is inconclusive as yet, (Singh et al. 1996). Some studies have found adherence positively related to contact with other seropositive people, (Hollander et al. 1988) or the presence of family, (Eldred et al. 1998). In

clinical trials, greatest adherence is reported by those with most social support, (Ickovics & Meisler, 1997).

Attitudes and Beliefs

An increasing body of research demonstrates the importance of cognitive factors such as attitudes and beliefs. Much of it has been conducted within the framework of the health belief model. As one might expect, those who see their drugs as having little benefit are less likely to adhere, Fernandez and Ruiz, (1989, cited in Mehta et al. 1997). The perception of HIV itself is important too, (Samet et al. 1992, cited in Eldred et al. 1997). The perceived severity of HIV and their perceived susceptibility to opportunistic infections are also related to adherence. Concern about taking medications in public has already been mentioned, (Ickovics & Meisler, 1997).

More relevant to this study are the findings about perceived self-efficacy. Thus far only two studies have considered the role of self-efficacy within adherence to treatment in HIV (Eldred et al. 1997, Durvasula et al. 1988). American research (Eldred et al. 1997) examined the relationship between perceived self-efficacy and adherence to antiretroviral monotherapy. This identified a significant correlation between self-efficacy expectations and adherence (OR=1.57; 95% CI 1.13, 2.17). Another study explored this relationship in HIV positive women. While the numbers of women infected with HIV are growing, (CDC, 1997, cited in Durvasula et al. 1988) men remain by far the largest group affected.

Disease Related Factors

Health Status

There is some evidence that health status is related to adherence, although the relationship is not an uncomplicated one. One of the few studies specifically investigating the impact of disease related factors on adherence in HIV found patients with lower CD4 cell counts were less adherent (Meisler, Ickovics, Walesky, Feller, Skowronski, & Friedland, 1993, cited in Ickovics & Meisler, 1997). They suggested that adherence may decline with disease progression although this would surely need to be cognitively mediated. They attribute this to a combination of *“physical and cognitive limitations, loss of belief in the efficacy of treatment and loss of social support with advanced disease”* (p. 388).

Singh et al. (1996) found people with experience of an opportunistic infection were more adherent. The authors argue, convincingly, that infections heighten perception of susceptibility to future infections. Asymptomatic people may consider themselves less vulnerable and be correspondingly less motivated in their adherence. *“An opportunistic infection or the presence of physical symptoms probably heightens the perceived severity of the illness and therefore the motivation of the patient to comply with therapy”* (Singh et al. 1996, p. 267).

Although this is intuitively plausible, it ought to mean that adherence is positively correlated with the presence of pain. Klosinski & Brooks', (1997) research suggests that the relationship is less simple. Using their dichotomous classification system, (adherent / nonadherent), 40% of people reporting moderate pain were non-

adherent as compared with 33% of people reporting no pain, and 31% reporting extreme pain.

Other findings from this study suggest that it may be change in health status that is the crucial variable. Those reporting an improvement in their health compared with a year previously reported significantly greater adherence than those for whom there was no change, or who experienced deterioration.

Medication Related Factors

The relationship between adherence and the length of time on medications has already been observed, at least as regards drug holidays. The longer the time spent on medication, the more days are taken as “drug holidays”.

It is clear that there is an inverse relationship between adherence and the number of medications taken, although it may be a function of the complexity of the regimen, (Ickovics & Meisler, 1997). The number of medications may be less important than dose frequency.

As one might expect, adherence also varies according to the type of medication, (Nakashima, 1988). Side-effects account for some of this variance. Anaemia, leukopenia and diarrhoea are known to decrease adherence, (Broers, Morabia, Hirschel, 1994, Samet, Libman, Steger, et al. 1992, Samuels, Hendrix, Hilton, Marantz, Sloan, Small, 1990, Easterbrook, Keruly, Creagh-Kirk, Richman, Chaisson, & Moore, 1991, all cited in Mehta et al. 1997).

Patient Provider Relationship

Healthcare practitioner-patient communication

One European study, (Hollander et al. 1988) found satisfaction with their physician was significantly correlated with adherence, (defined as less than two occasions of non-adherence over the previous two months).

Relationship issues may be particularly important with HIV positive injecting drug users. One study, (Broers, Morabia, Hirschel, 1994, and Gerbert, Maguire & Bleeker, 1991, cited in Mehta et al. 1997) suggested that physicians may have negative attitudes to injecting drug users and therefore make less effort to recommend combination therapy.

Interventions Targeting Adherence in HIV

Given the well established importance of adherence, one might expect a proliferation of intervention trials designed to increase adherence, but few research papers have been published as yet. Moreover, there seems to be a notable absence of psychological involvement in the four studies reported thus far, with the march stolen by pharmacists and occupational therapists. Unfortunately, only cursory information is available about these projects, three of which were presented at the 12th World Aids Conference in Geneva, and are currently only available in abstract form.

1.6 Theoretical Models

1.6.1 Health Belief Model

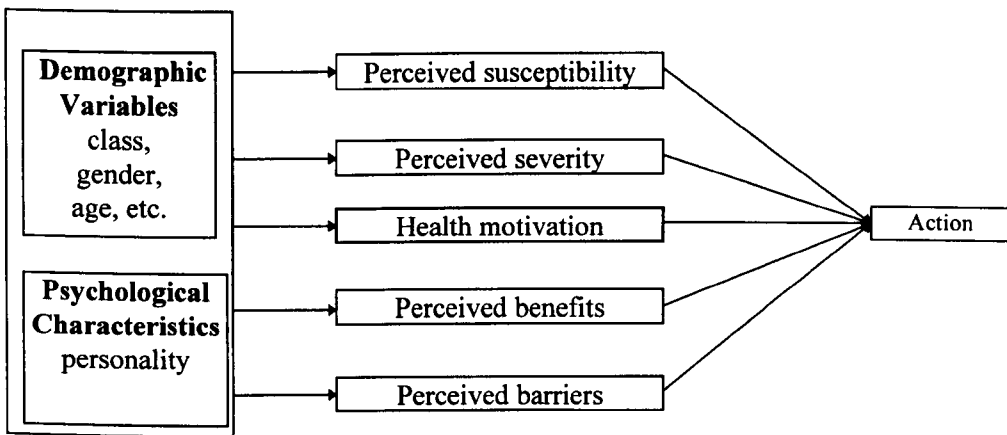
These findings have been considered within the theoretical framework of the Health Belief Model, (Rosenstock, 1966, Becker & Rosenstock, 1987, cited in Ogden, 1996) and the Theory of Reasoned Action (Ajzen & Fishbein, 1980, cited in DiMatteo et al. 1992). The Health Belief Model evolved from Social Cognitive Theory, (Bandura, 1977, 1986) which assumes that behaviour is determined by expectancies and incentives. Expectancies refer to beliefs about the probability that specific actions will produce particular outcomes or consequences. The subjective value or importance of those consequences are considered incentives. The value attached to health accounts for the performance of particular health behaviours, especially the adoption of disease prevention measures, and attendance for routine screening tests (in the absence of symptomatology) which the model was originally designed to predict. Health motivation determines behaviour in the context of the degree of perceived threat posed by the disease and the relative weighting of the risks and benefits associated with the recommended behaviour(s). The estimation of perceived threat is derived from an assessment of the perceived severity of the particular condition and the individuals perceived susceptibility to it.

The model generated a large amount of research investigating a wide range of health behaviours. Reviewing these studies, Horne & Weinman, (1998), conclude that the model is most useful as a predictor of preventative behaviours. They cite the meta-analysis conducted by Zimmerman & Vernberg, (1994, cited in Horne & Weinman,

1998) finding that the components of the Health Belief Model accounted for an average of 24% of the variance in preventative health behaviours.

They discuss a number of the model's limitations. Firstly, by neglecting the formation of behavioural intentions, it fails to specify the mechanisms whereby health beliefs determine behaviour. Secondly, the influence of social factors, such as the desire for others' approval remains undefined. Moreover this model may account for decisions about isolated events such as screening, but is unlikely to explain the complicated processes involved in maintaining health behaviours, such as adherence in chronic conditions.

Figure 1. The Health Belief Model (adapted from Horne & Weinman, 1998)



1.6.2 Theory of Reasoned Action

Ajzen & Fishbein, (1980, cited in DiMatteo et al. 1992) developed a theory which addresses two of the weaknesses of the Health Belief Model, by incorporating the influence of social factors, (subjective norms) and the central importance of behavioural intentions in predicting behaviour. The model suggests that volitional action is best

predicted by the intention to perform a particular behaviour. Behavioural intentions are formed on the basis of an individual's attitude towards the behaviour, their perception of social norms regarding it, and the value they place on the opinions of significant others. One might, for example, be highly motivated to adopt or maintain a behaviour because it is approved or deplored by a significant other(s). Attitudes towards behaviours are a combination of beliefs about the outcomes of the particular behaviour and an evaluation of the outcome. For example, one might have doubts about the relationship between smoking and cancer, but believe the benefits of giving up outweighed by the costs in terms of the difficulty and the loss of a strategy for coping with stress.

1.6.3 Perceived Self-Efficacy

Another strand of theoretical research has explored the role of self-efficacy in health behaviour, including adherence to medical recommendations. Self-efficacy theory has its origins in Social Learning Theory, (Bandura, 1977, cited in Kavanagh et al. 1993). The theory "*postulates that people's perceptions of their capabilities affect how they behave, their level of motivation, their thought patterns and their emotional reactions in taxing situations*" (O'Leary, 1985, p. 437). Perceived self-efficacy refers to people's judgements of their ability to perform particular behaviours to a specified level. Beliefs about the outcomes of the behaviour are termed outcome expectancies, and are considered conceptually distinct although the validity of this distinction has been questioned, (Eastman & Marzillier, 1984).

Efficacy expectations determine whether or not people will embark on a program of health related behaviour (diet, exercise, medication adherence) and affects the degree of commitment and persistence they display towards it. *“Adherence to difficult medical regimens by patients might thus be more consistent and longer lasting in those patients whose beliefs in their abilities to affect their health are strong”* (O’Leary, 1985, p.438).

Studies exploring the contribution made by efficacy expectations have demonstrated its utility in predicting sustained change in behaviours as diverse as smoking, pain management, diabetic dietary control, fluid restriction in renal failure, (Rosenbaum & Ben Ari-Smira, 1986, Schneider, Friend, & Whitaker, 1991) and alcohol use, (Kavanagh et al.1993).

Bandura (1997) argues that perceived self-efficacy affects mood as well as behaviour. *“Mood and perceived efficacy can influence each other bidirectionally. Perceived inefficacy breeds depression. Despondent mood diminishes perceived efficacy: positive mood enhances it, (Kavanagh & Bower, 1985).”* (Bandura, 1997, p.160). In his earlier work, Bandura, (1988) provided an account of the processes whereby perceived self-efficacy reduces vulnerability to depression, (Kavanagh et al. 1992, cited in Schwarzer, 1992). Evidence to support this thesis has been found from a study of patients with multiple sclerosis or spinal cord injury (Shnek, Foley, LaRocca, Gordon, Deluca, Schwartzman, Halper, Lennox, & Irvine, 1997).

Perceived self-efficacy also appears to affect the immune system. Bandura, (1997) cites epidemiological and correlational research demonstrating that lack of self-efficacy increases susceptibility to infection, contributes to the development of physical disorders and accelerates the rate of disease progression, (Peterson & Stunkard, 1989,

Schneiderman, McCabe & Baum, 1992, both cited in Bandura, 1997). Experimental studies have established that exposure to stressors which one has the ability to control has no adverse effects on the immune system, while exposure without control impairs it. Most fascinating of all, the process of self-efficacy attainment and mastery over phobic stressors appears to actively enhance immune functioning, (Weidenfeld, Bandura, Levine, O'Leary, Brown, & Raska, 1990). Moreover, these immunoenhancing effects persist such that Bandura, (1997) suggests they may serve a protective function in later times of stress.

As early as 1977, Bandura's research conclusively established that self-efficacy could be experimentally manipulated. Later work has demonstrated that clinical interventions can increase self-efficacy for changing health related behaviours such as smoking, (Condiotte & Lichtenstein, 1981, cited in Eldred et al. 1997) contraceptive use, (Gilchrist & Schinke, 1983, cited in Eldred et al. 1997) and exercise, (Ewart, Taylor, Reese & Debusk, 1984, cited in Eldred et al. 1997). Moreover, in these studies, increases in self-efficacy was related to subsequent changes in these behaviours. The clinical applications of self-efficacy acquisition have been extended to include pain management, the treatment of eating disorders, cardiac rehabilitation, (O'Leary, 1985) and hemodialysis, (Rosenbaum & Ben-Ari Smira, 1986).

1.6.4 Criticisms of Perceived Self-efficacy

Borkovec, (1978, cited in Kavanagh et al. 1993) has suggested that it is people's skills, not their self-efficacy which determines behaviour. Past performance levels provide a measure of someone's range and level of skill attainment (although these will also have

been influenced by self-efficacy expectations). According to this view, cogently expressed by Eastman & Marzillier, (1984) self-efficacy expectations may merely reflect accurate predictions of future performance based on assessment of past behaviour. As a result, much self-efficacy research has examined the relative contribution of performance and self-efficacy as predictors of subsequent behaviour. There is now an increasing body of research to suggest that self-efficacy is a better predictor than performance, (Condiotte & Lichtenstein, 1981, Kavanagh & Wilson, 1989, Kavanagh et al. 1993, Sitharthan & Kavanagh, 1990, Yusaf & Kavanagh, 1989, all cited in Kavanagh, 1993).

More persuasive still, experiments have been designed to test the proposition that self-efficacy is not a cause but a correlate of behaviour change. Litt's (1988) work exploring self-efficacy for cold-pressor pain tolerance tasks established that self-efficacy change predicted change in performance better than past performance or actual performance changes. As one might expect, this relationship is strongest where people have some experience of the task.

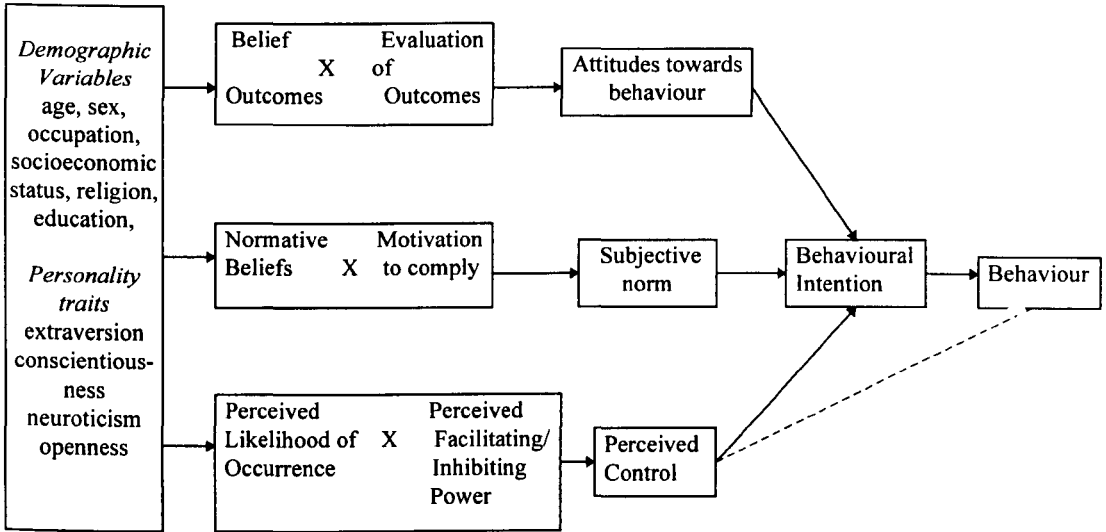
His experimental design also allowed him to test Bandura's (1982) proposition that people with high self-efficacy are likely to choose to exercise control where possible, while people with low self-efficacy are not, and indeed may experience distress and anxiety if forced to do so. The results of the study largely supported these hypotheses.

1.6.5 The Theory of Planned Behaviour

Such findings led Ajzen and colleagues (Ajzen, 1985, 1988, Ajzen & Madden, 1986, cited in Ogden, 1996) to modify the theory of reasoned action to incorporate other factors, renaming the updated version the Theory of Planned Behaviour. This incorporated an additional component termed perceived behavioural control, (the extent to which one considers a particular behaviour within one's control). The perception of control encompasses evaluation of the availability of internal and external resources, such as skills, abilities, and information, and the presence of environmental factors, help and hindrances. There are clearly similarities to the concept of perceived self-efficacy, (although it is measured by asking people to rate the relative ease/difficulty of particular behaviours, without the most crucial aspect for measuring self-efficacy, asking how easy/difficult the behaviour is for them).

The addition of perceived behavioural control improved the predictive power of the model which has been used to successfully predict a wide range of health behaviours. However, it has been criticised (Schwarzer, 1992) for underestimating the role of self-efficacy particularly as it affects the maintenance of health behaviours (as opposed to their initiation).

Figure 2. The Theory of Planned Behaviour (adapted from Horne & Weinman, 1998)



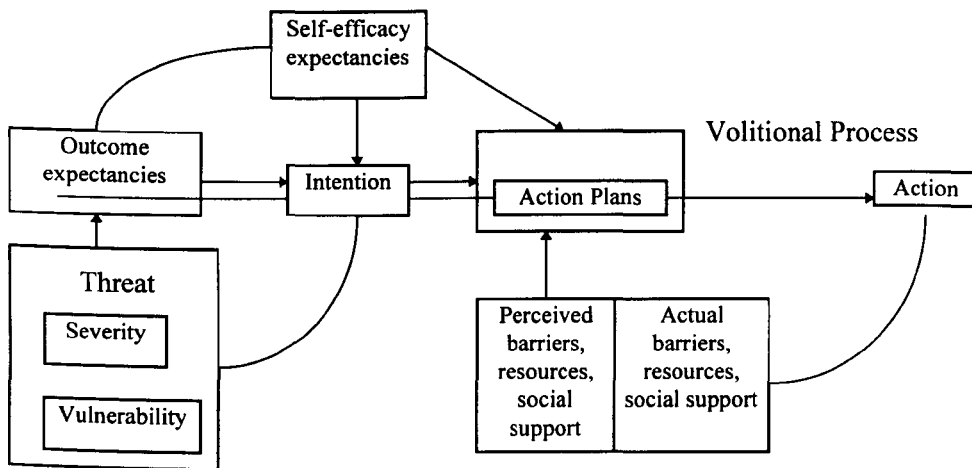
The Theories of Reasoned Action and Planned Behaviour have been used extensively to investigate behaviours from smoking cessation to the initiation of exercise regimes or condom use. They have also been used to successfully predict adherence to medication for urinary tract infections, (Reid & Christensen, 1988, cited in Horne & Weinman, 1998).

Nevertheless, while intention emerges as a strong predictor, it is common knowledge that intention alone does not predict behaviour. Empirical tests of the predictive power of this model have established that *“Health beliefs and motivation for health correlate better with behavioural intentions than with adherence behaviours, although the former affects the latter as noted above”*. (DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy & Marcus, 1993, p.102).

1.6.6 The Health Action Process Approach

Schwarzer's Health Action Process Approach (Schwarzer, 1992) conceptualises the initiation and maintenance of health behaviours as a process with two distinct phases, a motivational stage, followed by an action stage. People are seen as evaluating threats to their health in terms of their own individual vulnerability to any condition and consideration of its severity. These are then considered in the context of their expectations about outcomes. Self-efficacy expectations will inform outcome expectations, and thus intentions and plans for action. Perceived resources (such as social support) and barriers (financial constraints) further affect the volitional process.

Figure 3. The Health Action Process Approach (adapted from Schwarzer, 1992)



1.6.7 Integrating Perceived Self-Efficacy and the Transactional Model of Stress and Coping

It will be apparent that the Health Action Process Approach shares some features with Folkman & Lazarus' (1984) Stress and Coping model. The evaluation of threat in terms of individual vulnerability and severity constitutes primary appraisal. Consideration of coping resources can be conceptualised as a function of secondary appraisal.

1.6.8 The Transactional Model of Stress and Coping

Coping has been divided into emotion focused coping and problem focused coping. Appraisal evaluates the stressor as changeable or unchangeable. Where a stressor is accurately appraised as changeable, problem focused strategies are appropriate, but not if it is unchangeable, when emotion focused coping is required. Most stressors have both changeable and unchangeable aspects. Dysfunctional coping refers to a mismatch between the changeability of the stressor and the coping strategy employed. An HIV diagnosis clearly constitutes a major stressor, as is the requirement that one adhere to a rigorous pill taking schedule on an indefinite basis. As an unchangeable stressor, the diagnosis itself requires emotion focused coping, while adherence to medication is problem focused coping.

More recently it has been suggested (Carver et al. 1989, cited in Kennedy et al. 1995) that the distinctions between emotion and problem focused coping strategies are overly simplistic, and ignore the complexities of the coping process.

1.6.9 Coping and Perceived Self-Efficacy

Gattuso, Litt, & Fitzgerald (1992) have attempted to explore the relationship between coping and perceived self-efficacy. These researchers used the coping trait classification proposed by Shipley, Butt, & Horwitz, (1979, cited in Gattuso et al. 1992). This divides people into monitors (information seekers) and blunters, (information avoiders). Shipley et al. (1979, cited in Gattuso et al. 1992) advanced a congruency hypothesis arguing that information will be beneficial for monitors and may be detrimental for blunters. Gattuso et al. (1992) devised a self-efficacy enhancement intervention for men undergoing endoscopy procedures and compared monitors and blunters under four conditions: 1) self-efficacy intervention, 2) relaxation, 3) procedural information, 4) control group. Post-intervention self-efficacy predicted behavioural and physiological measures of distress during the procedure. Contrary to their predictions, although monitors performed best after the self-efficacy intervention, monitors did as well with self-efficacy as in any of the other conditions.

1.6.10 Coping in Chronic Conditions

Studies of coping in people with chronic conditions have established that there is considerable stability in the use of coping strategies over time, and some coping strategies are consistently associated with better psychological outcomes. On the basis of empirical evidence from a prospective study of coping in patients with spinal injury, Kennedy et al. (in press) concluded that adaptive coping was associated with the use of acceptance, active coping, positive reinterpretation and growth. Conversely, maladaptive coping was associated with behavioural disengagement, lack of acceptance,

and alcohol and drug ideation. Similar classifications have been made with HIV positive populations. Antoni, (1997) associated maladaptive coping with denial, mental disengagement and behavioural disengagement. Acceptance, active coping, positive reframing, and planning constituted adaptive coping strategies.

The relationship between avoidant coping and adherence in chronic conditions has already been mentioned, (Sherbourne et al. 1992).

1.6.11 Coping in HIV

In addition to the evaluation of interventions designed to increase adaptive coping in people with HIV, researchers have applied themselves to identifying the links between coping and other physical or psychological health indicators, such as immune functioning and depression. Some studies, (Ironson et al. 1994, Philips, 1992, cited in Mulder, Antoni, Duivenvoorden, Kauffmann, & Goodkin, 1995) have found significant relationships between coping strategies and disease progression. Mulder et al. (1995) found the use of active coping predicted decreased clinical progression after a year, which they suggested might be a product of increased adherence.

Avoidant coping in HIV on the other hand, has been found to be significantly correlated with depression, (Fukunishi, Negishi, Hayashi, Hosaka, Moriya, & Matsumoto, 1996).

1.6.12 Coping and Perceived Self-efficacy in HIV

The combination of perceived self-efficacy and choice of coping strategy in the context of perceived and real barriers and supports for adherence will determine an individual's secondary appraisal. *"Expectations of perceived self-efficacy determine whether coping behaviour will be initiated, how much effort will be expended, and how long it will be sustained in the face of obstacles and aversive experiences"* (Bandura, 1977, p.191).

The construct of coping self-efficacy (self-efficacy for coping with challenges and threats) has been investigated more fully in relation to HIV by Chesney, Folkman, & Chambers' (1996) work on coping effectiveness training.

Entitling this construct coping self-efficacy has the merit of defining more precisely the area to which the perceived self-efficacy refers, but is rather confusing if one wishes to consider the relationship between perceived self-efficacy and differential selection of coping strategies.

One study exploring these constructs separately in HIV (Sharts-Hopko, Regan-Kubinski, Lincoln, & Heverley, 1996) found perceived self-efficacy was inversely associated with measures of psychological distress, and positively associated with problem focused coping.

1.7 Rationale

Adherence to medication regimes is crucial for the treatment of people with HIV and prevention of the development of drug resistant viral strains. As yet, little is known about the risk factors of non-adherence and research has been empirically driven rather than theoretically grounded. Theoretical models permit a more structured analysis of the process, allow the development of predictions and indicate possible areas for intervention.

Studies of adherence in other chronic conditions have established the importance of perceived self-efficacy in adherence (Kavanagh et al. 1993). Researchers exploring this relationship in HIV have confined themselves to HIV positive women, (Durvasula et al. 1998) or were conducted when the only treatment available was monotherapy, which is much less effective than the new combination therapies. This study attempted to investigate the role of perceived self-efficacy in adherence in people with HIV including the relationship between perceived self-efficacy and other variables known to be associated with adherence. It aimed to address these issues with a UK HIV positive population. The Health Action Process Approach was chosen as the theoretical framework in which to locate the study because of the central role it assigns to perceived self-efficacy and also because of the emphasis given to the maintenance of health behaviours.

1.8 Research Aims

1. This study aims to investigate the role of self-efficacy in adherence to antiretroviral medication in people with HIV.
2. It will also explore the relationship between self-efficacy and coping strategies.
3. The relationship between self-efficacy and depression will be examined.

1.9 Statement of Hypotheses

- H1.** A positive relationship is predicted between perceived self-efficacy and adherence to combination drug therapies in HIV.
- H2.** An inverse relationship is predicted between self-efficacy and depression.
- H3.** Irrespective of depression level, it is predicted that perceived self-efficacy will account for a significantly greater proportion of the variance in adherence to antiretroviral medications than other variables known to be associated with adherence such as age, substance use, AIDS diagnosis, and side-effects.
- H4.** A positive relationship is predicted between perceived self-efficacy and adaptive coping strategies, such as acceptance, active coping, positive reframing, and planning.
- H5.** An inverse relationship is predicted between perceived self-efficacy and maladaptive coping strategies, such as denial, behavioural disengagement, self-distraction, and alcohol and substance use.
- H6.** Self-efficacy will account for a greater proportion of the variance than other Health Belief components of the Health Action Process Approach, (interpersonal aspects of care, perceived susceptibility, perceived severity, intentions, supports and barriers, and subjective norms).

2. Method

This section outlines the planning and implementation of the study and is subdivided as follows:

- Experimental Design
- Ethical Approval
- Participants
- Measures
- Treatment of Results
- Procedure
- Dissemination of Results

2.1 Design

This study employed a cross-sectional within subjects design. All participants completing an 283 item questionnaire at one time point. The dependent variables were four different measures of adherence: two global measures of adherence to dose times and adherence to special instructions, and two composite measures of dose omissions and dose delays. The independent variables were measures of perceived self-efficacy, coping strategies, depression levels, and a number of demographic, medication, and illness-related variables. All participants were given all measures.

2.2 Ethical Approval

Ethical approval for the study was sought and obtained from the East London and City Health Authority (hereafter ELCHA) subject to the consent of the consultants clinically responsible for patients (see Appendix I). Arrangements for dealing with distress elicited or uncovered by the study are outlined below.

2.3 Participants

Participants were recruited from HIV positive people attending routine clinic appointments at two linked HIV clinics in London, St Bartholomew's Hospital and the Royal London Hospital. All participants were volunteers over eighteen years old and taking antiretroviral therapies. Critically ill patients, those with severe psychiatric illnesses, and non English speakers were not approached for inclusion in the study.

2.4 Measures

Measures of demographic information, global and medication specific self-efficacy, global and medication specific adherence, mood, coping style, and health beliefs, were included. The full questionnaire is shown in Appendix IV. It consisted of the following self-report instruments which were selected for their reliability, validity, ease of administration and prior use with HIV infected populations and / or people with other chronic illnesses.

Independent Measures

2.4.1 Demographic Information Measure

This measure was derived from a questionnaire designed for a previous study conducted within the Royal London Hospitals Infection and Immunity Service, (Hedge & Petrak, 1998). It covered demographic information such as age, sex, ethnic origin, sexual orientation, first language and country of birth, and illness-specific information such as date of diagnosis, CD4 count, viral load, and disease status. It also assessed HIV antiretroviral medication combinations.

2.4.2 Mood

Anxiety and depression levels were assessed by the Hospital Anxiety and Depression Scale (HADS) a standardised fourteen item test, (Zigmond & Snaith, 1983) designed to provide a state measure of anxiety and depression without contamination by physical symptomatology. Each subscale has seven items. Respondents are asked to rate their agreement with statements with scores ranging from 0 to 3. Scores of 8-10 on each scale are taken to indicate possible psychiatric disorder, whilst scores of 11 or above suggest probable psychiatric disorder. Internal consistency is high with Cronbach Alpha scores of 0.93 and 0.90 for anxiety and depression respectively, (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson, & Bliss, (1991). The measure has considerable face validity with respondents finding it easy and acceptable. High concurrent validity has also been demonstrated (Zigmond & Snaith, 1983). This measure was selected for its reliability, validity, and frequency of use in comparable studies in HIV and other chronic illnesses.

2.4.3 Coping

Coping style was measured using a shortened (24 item) version of the COPE (Carver, Pozo, Harris, Noriega, Scheir, Robinson, Ketcham, Moffat, & Clark, 1993). This is an inventory of coping responses with a range of fifteen conceptually distinct scales.

Responses assessed by this measure range from aspects of problem-focused coping (e.g. active coping, planning) to the use of social support, turning to religion as a coping strategy, to positive reframing of the situation, to forms of avoidance coping (e.g. denial, behavioural disengagement). Response choices ranged from 1. I have not been doing this at all to 4. I have been doing this a lot. Scores for each scale are computed by adding the scores for each of the items.

The original COPE scales were developed from a factor analysis of 60 items. The alcohol/drug use and humour scales were developed after the other scales and are considered exploratory by the authors. They consider scales 1, 2, 5, 7, and 8 adaptive in situations where active coping yields good outcomes. Scales 3, 4, and 6, are thought probably adaptive in these situations. The authors comment that it is less clear what strategies would be most adaptive in dealing with uncontrollable aspects of the situation, such as the presence of HIV infection.

Different versions of the instructions mean the COPE can be used as either a dispositional measure (how one usually copes with stressful events) or a situational measure, (how one copes with specific situations or during a defined time period). In the current study the situational version was used, and participants were asked to rate their coping responses since diagnosis, (see Appendix IV for the full instructions).

Construct validity was tested for the original COPE, by comparing various personality traits thought to be associated with particular forms of coping. The active coping, planning, positive reinterpretation and growth subscales are positively correlated with measures of optimism and self esteem and negatively correlate with trait anxiety. Denial and behavioural disengagement displayed the opposite pattern.

The abbreviated COPE has two items for each scale. The focus of the scales was altered slightly in the process such that the positive reinterpretation and growth scale became positive reframing (questions tapping growth were excluded). Concentrating on and venting of emotions became venting, and mental disengagement became self-distraction. This shortened version was selected because of concerns about the participants' possible fatigue, given the length of the full questionnaire. Levels of internal consistency are adequate, (Cronbach's $\alpha > 0.5$) for all the scales (Carver, 1997).

2.4.4 Generalised Self-Efficacy

This was measured using the Generalised Self-Efficacy Scale (GSES) developed by Schwarzer and Jerusalem (1993, cited in Schwarzer, 1993). This ten item questionnaire *"assesses the strength of an individual's belief in his or her own ability to respond to novel or difficult situations and to deal with any associated obstacles and setbacks"* (Schwarzer and Jerusalem (1993, cited in Schwarzer, 1993, p. 220). Participants are asked to rate their degree of agreement with each statement. Responses range from 1. not at all true to 4. exactly true. The scores for each of the ten items are summed to give a total score. It should be noted that all the normative data has been collected from

German samples. However, high levels of internal consistency have been found in all the samples studied, with Cronbach's alphas ranging from 0.82 to 0.93. High test-retest reliability and adequate concurrent validity has also been established.

Factor analyses have been used to assess unidimensionality and a single factor solution has been found indicating that the GSES is measuring a unitary concept.

2.4.5 Medication Specific Self-Efficacy

Two aspects of Medication Specific Self-Efficacy were measured.

1. Self-efficacy for adherence to specific medications was assessed by adapting a question devised by Durvasula et al.(1998). These authors used an eleven point Likert scale which was reduced to a five point scale for the purposes of this study.

2. Self-efficacy for Medication Specific Problem Solving

This was assessed using a question devised by DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, (1993).

2.4.6 HIV Specific Health Beliefs

In the absence of a measure designed to test components of the Health Action Process Approach, the ADQ (DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993) was selected as measuring the health belief elements, namely: 1) perceived severity, 2) perceived vulnerability, 3) outcome expectancies, referred to as perceived utility, 4) intention, 5) presence of perceived supports and

absence of perceived barriers. This measure does not directly assess social support, but assesses the normative influence of significant others. Additional items to measure self-efficacy were inserted.

HIV Specific Health Beliefs were measured by adapting the 38 item Adherence Determination Questionnaire (DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993) for use with an HIV positive population. The ADQ was designed to measure the components of the Health Belief Model. Adequate reliability (median alpha reliability .76) for these components has been established. The ADQ was used as a framework into which questions from other studies of health beliefs within HIV positive people were incorporated. Thirty items were included from a study by Catt, Stygall, & Catalan, (1995) exploring the acceptance of AZT monotherapy in early HIV disease. Also inserted were a further 20 questions from an American study by Rossman & Goetz (1998) into adherence to combination therapies. Ten items developed by Eldred et al. (1998) to assess perceived self-efficacy for medication adherence were also included. Four additional items (assessing the subjective influence of doctors and partners) were devised by the author. The modified questionnaire consisted of 106 statements to which the participants rated the extent of their agreement on a five point Likert scale ranging from 1= strongly agree to 5= strongly disagree. The components measured were Interpersonal Aspects of Care, exploring the relationship with health professionals, specifically, Communication, (four items), and Rapport, (five items) Intention to Adhere, (seven items), Perceived Susceptibility to Disease Progression, (14 items) Perceived Severity of Disease, (11 items) and Perceived Utility (Costs/ Benefits of Therapy) (12 items), and the Presence of Perceived Supports and

Absence of Perceived Barriers to treatment (12 items). Subjective norms (assessing five normative expectations [aspects of the regimen by five sources, doctor, family, friends, partner, and relatives, multiplied by the respondents desire to conform to the wishes of these normative people: as recommended by Ajzen & Fishbein, 1980, cited in DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993]. Also included were 18 items measuring Perceived Self-Efficacy.

Following DiMatteo et al. (1993) the influence of each normative target was assessed with two statements, eg. 1. *My relatives think I should follow my treatment plan.* 2. *I want to do what my relatives think I should do about my treatment plan.* As recommended by Ajzen & Fishbein, (1980, cited in DiMatteo, Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993), scores on the two statements were multiplied to form a score for each of the five social norm sources: doctor, family, friends, partner, and relatives. Responses were recoded according to the recommendations of Ajzen & Fishbein, (1980, cited in DiMatteo Hays, Gritz, Bastani, Crane, Elashoff, Ganz, Heber, McCarthy, & Marcus, 1993): for Motivation (2.), Strongly agree=3, Agree=2, Neither agree nor disagree=1, Disagree, and Strongly Disagree=0; for Normative Belief (No.1), Strongly agree=2, Agree=1, Neither agree nor disagree=0, Disagree=-1, and Strongly Disagree=-2.

Dependent Measures

2.4.7 Treatment Adherence Measures

Global and medication specific self-reported adherence was assessed using measures developed for the study reported earlier, (Hedge & Petrak, 1998). The adherence questions encompass three dimensions of adherence, 1. dose timing, 2. dose omissions and 3. changes to dosage levels. Participants also indicated what happened on the last occasion that their medication taking routine was disrupted.

2.5 Treatment of Results

Statistical Analysis

Participant demographics, psychological indices, and medication adherence levels were entered into a database (SPSS 9.0 for Windows). Kolmogorov-Smirnov Goodness of Fit tests were performed on the variables under consideration, to investigate whether they were normally distributed. A number of variables were found to be non-normally distributed in the total sample, non parametric statistics were applied to these variables. Multiple and stepwise regression models were used to evaluate factors associated with non-adherence.

2.6 Procedure

All participants completed the questionnaire, which took approximately 30 - 45 minutes. The method of recruitment differed slightly between sites. All participants were approached on routine clinic visits, either directly, (at the Royal London Hospital) or after referral by their consultant physician, (St Bartholomew's Hospital) and invited to

participate in the research study. Those that expressed an interest were then provided with further information about the study both orally and in the form of an information sheet (see Appendix II). They were also offered the opportunity to ask questions about the study. Those people who agreed to participate in the study were asked to read and sign a consent form (see Appendix III). Participants were offered a private room in which to complete their questionnaire but some preferred to remain in the waiting room.

Arrangements were made to cope with possible distress occasioned by participation in the study. Questionnaires were completed with the researcher present. Participants were to be awaiting an appointment with a clinician with whom such issues would routinely be discussed. Should participants become distressed after leaving the clinic, the information sheet provided a contact number for those wishing to access psychological support from one of the investigators. However, no participant expressed distress and several commented on beneficial aspects of participation. For the most part, this entailed feeling the difficulties of adherence were being taken seriously, and feeling that their personal experience was valued and might contribute to the furtherance of knowledge about adherence. Participants were informed that a summary of the results of the study would be available from the clinic reception once the study was completed.

2.7 Dissemination of results

A summary of the findings of the study is planned and will be circulated to the St Bartholomew's and the Royal London Infection and Immunity Service. Copies will also be available at the clinic reception for participants and other interested service users.

3. Results

This section will outline the results obtained which are presented in the following order:

- sample size
- descriptive data for the dependent and independent variables
- investigation of the hypotheses.

3.1 Sample size.

52 participants completed questionnaires, although many people omitted some items.

3.2 Descriptive data for the dependent and independent variables

Age

The mean age of participants was 38.29 years, with ages ranging from 22-69, (SD 9.59).

Sixteen people, (34 %) were under 34 years old, only one participant was under 25. One participant (1.9%) did not provide information about their age.

Sex

Over three quarters of respondents, (78.8%) were male and 19.2% female. One respondent (1.9%) did not identify their sex.

Cultural Background

Over half the sample, (53.8 %) identified as of white, UK backgrounds. Six people (11.5%) described themselves as of European origin, and one person, (1.9%) as Jewish. Eleven people (21.1%) identified as black, (including people of Caribbean and African descent). Two people (3.8%) reported Chinese backgrounds and a further two described themselves as Latin American. One person, (1.9%) identified as Vietnamese.

Language

Almost three quarters, (73.1%) of participants described English as their native language. Other first languages included Amharic, Chichewa, Chinese, French, Luo, Portugese, Somali, and Spanish.

Current Relationships

Over half the sample (59.6%) indicated that they had a current regular partner, while 40.4% reported that they did not.

Duration of Current Relationships

These relationships ranged from two months to thirty one years.

Sexual Orientation

All the women were heterosexual, while all the men except two (95.1%) were gay. Two respondents did not identify their sexual orientation.

Domestic Circumstances / Living Arrangements

Twenty four people (46.2%) lived alone, and 23, (44.2%) shared with their partner. One person, (1.9%) lived with a friend, one with their parents, one with their children, one in prison, and one in a community specifically for HIV positive people.

Substance Use

A quarter of the sample, (13 participants) reported no alcohol consumption, whilst the maximum number of units drunk per week was 30. The mean number of units was 7.08 per week, (SD 8.72).

Twenty one people, (40.4 %) indicated that they used some recreational drugs (i.e. cannabis, ecstasy, cocaine, speed, amyl nitrate, or valium). An equal proportion reported that they never used street drugs, and 10 people, (19.2 %) declined to answer the question. Cannabis was the most popular recreational drug, with 11 people, (21.2%) reporting at least occasional usage.

Mood

Anxiety scores for this population ranged from 0-19 with a mean score of 6.96 (SD 4.86). Eight people (15%) obtained a score between 8 and 10 indicating possible psychiatric disorder. Twelve, (23%) scored over 10 indicating probable psychiatric disorder. The mean depression score was lower, (4.90, SD 4.32) although the range was the same, (0-19). The scores for six people (12%) fell into the possible psychiatric disorder range, and six (12%) into the probable psychiatric disorder category.

Coping

From table 1 it can be seen that the sample utilised the full range of coping strategies with acceptance being the most widely used, followed by planning, emotional disengagement, positive reframing, humour and self-distraction.

Table 1. Coping Strategies

	Range	Mean	SD.
Self-distraction	1-8	4.40	1.76
Active Coping	2-8	5.25	1.63
Denial	1-8	2.81	1.52
Alcohol and Drug Use	2-8	3.10	1.77
Emotional Disengagement	2-8	4.88	1.94
Behavioural Disengagement	1-8	2.69	1.50
Venting	2-8	3.69	1.58
Positive Reframing	2-8	4.83	2.13
Planning	1-8	5.29	1.82
Humour	1-8	4.56	2.23
Acceptance	2-8	7.04	1.56
Religion	2-8	3.52	2.23

Perceived Self-efficacy

GSES

The mean Generalised Self-Efficacy Score was 31.06 (range 14-57, SD, 7.04). This is higher than the mean score of 29.28 (SD 4.6) obtained by Schwarzer (1993) from his German sample, but is not significantly different. The standard deviation in this sample is clearly greater.

Medication-specific Self-efficacy

Self-efficacy for adherence to specific medications.

The mean score for the Composite measure of Self-efficacy for adherence to specific medications was 4.3925, (range 1-5, SD. 8.382).

Self-efficacy for Medication-specific Problem Solving

The mean score for the Composite measure of Self-efficacy for Medication-specific Problem Solving was 4.2343, (range 1-5, SD. 9.884).

Table 2. Summary statistics and reliabilities for the adapted Health Belief scales of the ADQ.

Table 2 illustrates that adequate alpha reliabilities were obtained for all the sub-scales of the ADQ with the exception of Subjective norms.

Scale	No. of items	Range Transformed 0-100	Mean Transformed 0-100	SD Transformed 0-100	Alpha Reliability
Interpersonal Aspects of Care	9	50-100	78.6423	13.1659	.6857
Perceived Utility	24	26.04-93.75	72.57	13.5160	.8693
Perceived Susceptibility	14	11.54-78.57	47.9798	13.0068	.7474
Perceived Severity	11	34.09-90.91	57.9545	13.2189	.5464
Intentions	7	7.14-100	84.5238	20.0593	.8974
Supports and Barriers	12	22.92-100	67.0451	15.7553	.7719
Perceived Self-Efficacy	18	5.56-100	79.8458	14.7147	.8980
Subjective Norm	5	43.33-100	62.4797	13.2849	.21

Table 3. Inter-correlations between adapted ADQ subscales

The inter-correlations between the ADQ subscales presented in Table 3 illustrate that the constructs measured by these subscales are not mutually exclusive.

	Interperson al Aspects of care	Perceived Utility	Perceived Susceptibil ity	Perceived Severity	Intentions	Perceived Supports and Barriers	Perceived Self- efficacy	Subjective Norm
Interperson al Aspects of care	1	.350*	-.010	.111	.090	.346*	.065	.259
Perceived Utility	.350*	1	-.083	.065	.590**	.685**	.788**	.504**
Perceived Susceptibil ity	-.010	-.083	1	.273	.039	.041	-.033	-.120
Perceived Severity	.111	.065	.273	1	.186	.042	.097	-.055
Intentions	.090	.590**	.039	.186	1	.642**	.695**	.208
Perceived Supports + Barriers	.346*	.685**	.041	.042	.642**	1	.715**	.228
Perceived Self- efficacy	.065	.788**	-.033	.087	.695**	.715**	1	.311*
Subjective Norm	.259	.504**	-.120	-.055	.208	.228	.311*	1

Significance levels * $p < .05$ ** $p < .01$

Illness Specific Information

Participants' health status covered a wide spectrum. CD4 counts ranged from a minimum of 21 to a maximum of 850, with a mean of 328.38 (SD 161.51). Seventeen people (32.7%) had undetectable viral loads, and four (7.6%) were in the 10-15,00 range. The maximum viral load was 300,000. The length of time since their HIV diagnosis ranged from six months to 16.5 years with a mean of 7.2 years, (SD 4.3806). Twenty-nine respondents, (56.9%) did not have an AIDS diagnosis while 22, (42.3%) did. One person did not answer this question.

Medications Taken and Prevalence of Reported Side Effects

The sample were taking different combinations of a total of 16 medications, see Table 4. There was a total of 41 different drug combinations. Excluding drugs for PCP prophylaxis, there were 35 antiretroviral drug combinations, which makes it impossible to analyse the adherence data by drug combination.

Twenty-seven people (52%) reported experiencing side effects associated with 11 drugs. The most frequently reported side effect was diarrhoea. The drugs associated with the greatest number of side effects were d4T, Indinavir, and Nevirapine. Over half of those taking Indinavir, and half of those taking Nelfinavir reported side effects. Over a third of those taking AZT described side effects as did just under a third of those on d4T.

Table 4. Medications Taken and Prevalence of Reported Side Effects

Medication	Frequency	Percent	No of People Reporting Side-effects	Side Effects Reported
AZT	11	21.2%	4	Diarrhoea, nausea, and fatigue
ddi	19	36.5%	5	Peripheral neuropathy, diarrhoea, nausea, and headache
ddc	2	3.8%	0	
d4T	34	65.4%	11	Peripheral neuropathy (7) diarrhoea, nausea, insomnia, headache, and tardive dyskinesia.
3TC	28	53.8%	4	Peripheral neuropathy (2), diarrhoea, and insomnia
Nelfinavir	6	11.5%	3	Diarrhoea and lipodystrophy
Ritonavir	3	5.8%	1	Diarrhoea and lipodystrophy
Saquinavir	7	13.5%	2	Peripheral neuropathy (1), and diarrhoea
Indinavir	14	26.9%	9	Diarrhoea, post dosage discomfort, lipodystrophy,(4), dermatological problems, nausea, insomnia, headache, fatigue, flatulence, and tardive dyskinesia.
Nevirapine	21	40.4%	4	Peripheral neuropathy, diarrhoea, dizziness, dermatological problems, nausea, headache
Delavirdine	0	0%	0	
dmp	4	7.7%	0	
Abacavir	5	9.6%	0	
Combivir	3	5.8%	0	
Septrim	14	26.9%	1	diarrhoea
Dapsone	1	1.9%	1	diarrhoea
Aerosolised Pentamidine	4	7.7%	0	

Adherence

This section is divided into Self-Perceived Adherence, Global Medication Adherence, (two measures), Medication-specific Adherence, (four measures) and three Composite Adherence Measures. This yields a total of 10 adherence measures. The Global measures refer to participants' responses to general questions about their adherence. The composite measures are calculated by summing medication-specific adherence measures for each drug.

Person Specific Adherence

- 1) Self-Perceived Adherence,**
- 2) Global adherence to dose times,**
- 3) Global adherence to special instructions,**
- 4) Composite dose omissions**
- 5) Composite dose delays**

Medication-specific Adherence

- 6) Doses missed**
- 7) Dose delays**
- 8) Adherence to special instructions**
- 9) Frequency of disruption to drug routine**
- 10) Composite frequencies of disruptions to
drug routine for entire sample**

This is followed by a section presenting more data on disruptions to drug regimes including 1) attributions for the last lapse,

- 2) triggers for the realisation that a disruption to the routine had occurred
- 3) individual beliefs about medication efficacy given the way they take their medications.

Person Specific Adherence

1. Self-Perceived Adherence

42.3% of the sample considered themselves excellent at taking the drugs as prescribed. Half described themselves as good, 3.8% as reasonable and 1.9% as poor. One person declined to answer the question.

Global Medication Adherence

2) Global adherence to dose times,

A quarter of the sample (25%) said they never changed their dosage times. 34.6% indicated that they did so occasionally, 25% sometimes, 9.6% usually, and 3.8% always. One person did not complete this question. Only one person, (1.9%) reported that they sometimes altered the drug dosage. Two people did not answer this question.

3) Global adherence to special instructions,

Almost half the sample, (48.1%) said they never took their drugs without adhering to the prescribed regimen. A quarter indicated that they occasionally did, and 19.6% did so sometimes. 5.8% reported that this was a usual occurrence and 3.8% that it always happened. Three people did not respond to this question.

When asked whether they ever took drug holidays, 76.9% said they never did so and 21.2% replied that they occasionally did.

4. Composite dose omissions

No respondent reported missing a dose on the previous day. The total number of days on which doses were missed by this sample during the previous week was 48. Thirty seven people, (71.2% of the sample) indicated that they had not missed a dose on any day during the previous week. Fourteen people, (26.9%) had missed doses on one or more days. The number of days on which doses were missed by an individual during the previous week ranged from 0-7, with a mean of .9412, (SD 1.8912).

5. Composite dose delays

No respondent indicated that they had taken a dose late on the previous day. A total of 111 doses were taken late by this sample during the previous week. Thirty people (57.7% of the sample) reported that they had not taken a dose late during the previous week. Nineteen people, (36.5%) indicated having taken one or more doses late. The number of doses taken late by an individual during the previous week ranged from 0-25, with a mean of 2.2653, (SD 4.9065).

Medication-specific Adherence**6. Dose omissions and 7. Dose delays**

Table 5 presents data for dose omissions and dose delays by type of medication taken.

Although the numbers taking each medication were insufficient to permit statistical analysis, the percentages on each medication reporting dose omissions or dose delays demonstrate wide variation. It is interesting that for some medications, no individuals reported missing or omitting doses. At the other end of the spectrum, 42.9% of those taking Indinavir reported dose delays.

Table 5. Dose Omissions and Dose Delays

	Dose Omissions					Dose delays				
	No of people omitt-ing doses by Mx	% of people on Mx omitt-ing doses	No of days	Mean no of days per total on Mx	SD	No of people delay-ing doses by Mx	% of people on Mx delay-ing doses	No of days	Mean no of days per total on Mx	SD
Medication										
AZT	0	0	0	0		2	18%	4	0.57	(1.13)
ddi	4	21.1%	8	0.4706	(0.9432)	4	21.1%	19	1.375	(2.918)
ddc	0	0	0	0		0	0%	0	0	
d4T	4	11.8%	5	0.1667	(0.4611)	7	20.6%	29	1.0357	(2.3802)
3TC	5	17.9%	7	0.3182	(0.6463)	4	14.3%	10	0.5556	(1.2935)
Nelfinavir	1	16.7%	1	0.25	(0.5)	1	16.7%	2	0.5	(1.0)
Ritonavir	0	0%	0	0		1	33.3%	1	0.3333	(0.5774)
Saquinavir	2	28.6%	2	0.3333	(0.5164)	1	14.3%	1	0.1429	(0.378)
Indinavir	2	14.3%	4	0.3077	(0.7511)	6	42.9%	12	0.8571	(1.4064)
Nevirapine	4	19.1%	12	0.6	(1.6351)	6	28.6%	18	1.1875	(2.0073)
dmp	1	25%	2	0.6667	(1.1547)	1	25%	2	0.6667	(1.1547)
Combivir	0	0	0	0		1	33.3%	3	0.667	(1.1547)
Abacavir	0		0	0		1	20%	3	1.0	(1.7321)

8) Adherence to special instructions

Table 6 presents data on adherence to the special instructions for taking each drug. It should be noted that some drugs (such as those for PCP prophylaxis) do not have special requirements for their consumption, so the data on PCP prophylaxis has not been presented. Drugs with asterisks have special requirements, drugs with two asterisks, (protease inhibitors) require especially strict adherence to dietary restrictions and dose times.

Table 6. Adherence to Special Instructions

Medication	Always adhere to special instructions		Usually adhere to special instructions		Adhere to special instructions 50% of time		Occasionally adhere to special instructions		Never adhere to special instructions	
	n	%	n	%	n	%	n	%	n	%
AZT			1	9%						
ddi*	6	32%	5	26%	1	5%	1	5%	1	5%
ddc	1	50%								
d4T*	5	15%	4	12%			1	3%	2	6%
3TC*	4	14%	4	14%					1	4%
Nelfinavir**	1	17%	2	33%						
Ritonavir**	2	67%	1	33%						
Saquinavir**	1	14%	2	29%	2	29%				
Indinavir**	4	29%	5	36%			3	21%		
Nevirapine**	5	24%	1	5%					1	5%
dmp	1	25%								
Abacavir										
Combivir										

7. Frequency of disruption to drug taking regime

Table 7. Frequency of Disruption to Drug Regime

	Daily	Almost daily	3-4 times weekly	1-2 times weekly	2-3 times monthly	Once a month	Less than once a month
% dose disruptions if twice daily regimen	50%	38%	29%	14%	5%	2%	
% dose disruptions if 3 x daily regimen	33%	24%	19%	10%	4%	1%	
approx. % range of adherence	50-67%	62-76%	71-81%	86-90%	95-96%	98-99%	100%
Medication							
AZT					4	1	2
ddi			1	3	5	2	4
ddc				1			
d4T		1	1	1	1	5	15
3TC	2	1		1	3	3	10
Nelfinavir					1	2	1
Ritonavir						1	
Saquinavir					2	2	2
Indinavir				2	1	1	6
Nevirapine	1			1	1	4	7
dmp						1	
Abacavir							2
Combivir						1	2
Septtrim							4
Dapsone		1					
Aerosolised pentamidine	1						

10. Composite frequencies of disruptions to drug routine for entire sample

(calculated by summing responses for each drug)

Table 8 illustrates that almost half the sample indicated that disruptions to their routine were rare, occurring less than once a month. 16% of the sample reported disruptions occurring at least once a week.

Table 8. Composite Frequencies of Disruptions to Drug Routine

Frequency	Count	% of Responses
Every day	5	4.2
Nearly every day	3	2.5
3-4 times weekly	2	1.7
1-2 times weekly	9	7.6
2-3 times monthly	18	15.3
Once monthly	23	19.5
Less than once monthly	58	49.2

Self reported explanation for last disruption to regime

Table 9 illustrates the reasons reported for the last disruption to their regime. Just over a fifth of disruptions were attributed to being out of the house or away from their medications. Other major factors included falling asleep, and changes to their eating routine.

Table 9. Self Reported Explanation for Last Disruption to Regime

Explanation	Frequency	% of responses
Don't know	1	.9
Excess alcohol or recreational drugs	4	3.7
In hurry	4	3.7
Did not want to take medication in front of others	5	4.7
Ran out of medications	5	4.7
Depressed	6	5.6
Side effects	7	6.5
Distracted	10	9.3

Factors leading to realisation that routine had been disrupted

The most salient feature of the data presented in Table 10 is that three quarters of those providing data about factors involved in the realisation that doses had been missed, had realised spontaneously without prompts from people, alarms, or the cues provided by external events.

Table 10. Factors Leading to Realisation that Routine had been Disrupted.

Factor	Frequency	% of Responses
Reminded by another person	4	4.1
Reminded by timer or beeper	6	6.1
Had leftover pills in planner/bottle	7	7.1
Reminded by other scheduled events	8	8.2
Spontaneously remembered	73	74.5

Perceived Benefit

Table 11 presents the data on perceived benefit of drugs. Half the sample believed they derived all possible benefit from their drugs. A quarter indicated that taking their drug taking behaviour into account, they think they get most of the benefit from their drug. One fifth consider the benefit obtained enough to make it worth taking, and only 1.8% reported believing the benefits obtained were less than that.

Table 11. Perceived Benefit

Degree of benefit	Count	% of responses
Not much benefit	2	1.2
Some benefit	1	.6
Enough to make it worth taking	31	19.1
Most of the benefit	38	23.5
All possible benefit	89	54.9

3.3 Investigation of the Hypotheses

H1. A positive relationship is predicted between perceived self-efficacy and adherence to combination drug therapies in HIV.

Correlations

Spearman's rho correlation coefficients were calculated for the three perceived self-efficacy measures and the four adherence measures, see Table 12.

GSES

No significant correlations were observed between GSES scores and the global measures of adherence to dose times, or adherence to special instructions. There was a modest negative correlation with the composite measure of dose omissions, ($-.398$, $p < .01$) but no significant correlation with the composite measure of dose delays.

Self-efficacy for adherence to specific medications

No significant correlations were observed between scores for self-efficacy for adherence to specific medications and the global measures of adherence to dose times, or adherence to special instructions. However, it was negatively correlated with both the composite measure of dose delays, ($-.315$, $p < .05$) and the composite measure of dose omissions, ($-.548$, $p < .01$).

Self-efficacy for Medication-specific Problem Solving

A similar but weaker pattern was observed for self-efficacy for medication-specific problem solving and adherence. There were no significant correlations with the global measures of adherence to dose times, adherence to special instructions, or the composite measure of dose delays. A significant negative correlation was obtained with the composite measure of dose omissions, ($-.367, p < .01$).

Table 12. Table of Correlations between Age, Depression score, Alcohol Consumption, General and Medication-specific Self-Efficacy and the Four Adherence Measures.

	Global adherence to dose times	Global adherence to special instructions	Composite dose omissions	Composite dose delays
Age	-.083	.031	-.349**	-.121
HADS depression score	-.066	.224	.341**	.059
Units of alcohol consumed per week	.095	-.113	-.023	-.050
Generalised Self-efficacy Score	-.081	.077	-.398**	-.123
Self-efficacy for adherence to specific medications	-.144	-.143	-.548**	-.315*
Self-efficacy for Medication-specific Problem Solving	.066	.046	-.367**	-.149

Significance levels * $p < .05$ ** $p < .01$

H2. An inverse relationship is predicted between self-efficacy and depression.

A Pearson's correlation coefficient was calculated using the HADS depression score and Generalised Self-efficacy Score. The correlation coefficient was calculated as $r = -.409$ ($p < .01$). This suggests that depression and Generalised Self-efficacy are related, although distinct phenomena. However, there is some doubt as to whether it is appropriate to use the HADS as a linear measure, and it has been suggested that it is best used as a categorical measure. Therefore, the recommended cut-offs were used to group the HADS scores into nonclinical, possible, and probable psychiatric disorder populations. A one-way Anova was performed (including Sheffe and LSD post-hoc analyses). This established that there was a significant difference between groups ($F = 6.198$, $p = .004$). Post-hoc tests identified that the differences in GSES scores lay between the non-clinical and the possible psychiatric disorder group, ($p > .01$). However, there were no significant differences between those with probable psychiatric disorder and the other two groups.

Examination of the means for the three groups suggests that the explanation for this may lie in the spread of GSES scores of those with probable psychiatric disorder. The mean GSES score for the non clinical group was 32.71, (SD 6.16), for the possible psychiatric disorder group, 23.33, (SD 5.85), and the probable psychiatric disorder, 27.50, (SD 9.09).

-
- H3. Irrespective of depression level, it is predicted that perceived self-efficacy will account for a significantly greater proportion of the variance in adherence to antiretroviral medications than other variables known to be associated with adherence such as age, substance use, depression, AIDS diagnosis, and side effects.**

After computing the correlations between age, substance use, depression, GSES, the two medication-specific self-efficacy measures and the dependent variables, the four person-specific adherence measures, (global adherence to dose times, global adherence to special instructions, composite dose omissions, and composite dose delays) the third hypothesis was tested by calculating four sets of regression analyses using the four adherence measures to assess the relative predictive power of those variables known to be related to adherence to antiretrovirals.

Normal distribution could not reasonably be assumed for the four adherence variables so Spearman's rank correlations coefficients were calculated, (see Table 12). Since an AIDS diagnosis and the experience of side-effects are categorical measures, Mann Whitney *U* tests were conducted.

Age

Age was not significantly correlated with the measures of global adherence to dose times, global adherence to the special instructions, or the composite dose delays. There was, however, a weak negative correlation, (-0.349 , $p < 0.01$) with the measure of

composite doses missed. This finding is in keeping with the results from other studies which find adherence increases with age.

Substance Use

Alcohol

No significant correlations were observed with any of the four adherence variables.

Recreational Drug Use

Since whether or not people engage in recreational drug use is a categorical measure, Mann Whitney *U* tests were performed with each of the four adherence measures. No significant results were obtained.

Depression

The HADS depression scores were not correlated with the measures of global adherence to dose times, global adherence to the special instructions or the composite measure of dose delays. On the other hand there was a statistically significant correlation with composite doses omissions, (.341, $p < 0.01$). When Mann Whitney *U* tests were conducted using the HADS as a categorical measure, no significant associations were found with any of the four adherence measures.

AIDS diagnosis

A Mann-Whitney *U* test was conducted for AIDS diagnosis with each of the four adherence variables. No statistically significant results were obtained with the global measures of adherence to dose times, or adherence to special instructions, or the composite measure of dose omissions. However, a statistically significant inverse association was observed with composite dose delays ($z = -2.619$, $p > 0.05$). This is unexpected given that previous research has found that people with prior experience of opportunistic infections, (one of the defining criteria for an AIDS diagnosis) display greater adherence.

Side-Effects

Whether or not participants experienced side-effects is also a categorical measure, so Mann-Whitney *U* tests were conducted. No statistically significant associations were observed with any of the four adherence variables.

Perceived Self-efficacy

The correlations for GSES, and medication-specific self-efficacy have already been presented in relation to the first hypothesis, see Table 12.

Regressions

Multiple Regressions

All the above measures were put into the regression analyses. Each regression was calculated twice, initially using the total HADS depression scores, and subsequently using it as a categorical measure in a stepwise regression, although this did not appear to affect whether predictors of adherence emerged from the analyses.

1) Global adherence to dose times,

Multiple Regression

When the global measure of adherence to dose times was used as the dependent variable, the proportion of the variance accounted for was 18.6%, ($F=.661$, NS). This was insufficient for any individual variable to emerge as a statistically significant predictor.

Stepwise Regression

Conducting a stepwise regression with depression classified as absent or possibly present, only 4.5% of the variance was accounted for, ($F=.328$, NS) which was insufficient for any single variable to emerge as a significant predictor.

2) Global adherence to special instructions,

Multiple Regression

Substituting global adherence to special instructions as the dependent variable increased the proportion of the variance accounted for to 24.8%, ($F=.877$, NS). However, no significant predictors were identified by the analysis.

Stepwise Regression

Using the categorical measure of depression in a stepwise regression, 8.5% of the variance was accounted for, ($F=.610$, NS).

3) Composite dose omissions

Multiple Regression

Using the composite measure of dose omissions as the dependent variable, 39.7% of the variance was accounted for, ($F=1.830$, NS). However, only the use of recreational drugs emerged as a significant predictor, see Table 13. Only the significant predictor is included in the table.

Table 13. Multiple regression analysis for composite dose omissions

Dependent variable	Independent variables	Beta	t	R Square	d.f. (total)
Composite dose omissions	Use of recreational drugs	.445	2.386*	.397	25

Significance level * $p<.05$

Stepwise Regression

To investigate whether other variables would emerge as significant once recreational drug use was controlled for, a stepwise regression was conducted entering recreational drug use as the first variable, see Table 14. Recreational drug use accounted for 15.6% of the variance, ($F=6.120$, $p>.02$) when this was controlled for, self-efficacy for adherence to specific medications emerged as a significant predictor, adding a further 12.7% of the variance, ($F=6.324$, $p>.005$).

Table 14. Stepwise regression analysis for composite dose omissions

Dependent variable	Independent variables entered stepwise	Beta	t	R Square	d.f. (total)
Composite dose omissions	Use of recreational drugs	.396	2.474	.156*	32
	Self-efficacy for adherence to specific medications	-.357	-2.380	.283***	

Significance levels * $p<.02$ ** $p<.01$ *** $p<.005$

Recalculating the stepwise regression analysis with the categorical measure of depression as the first variable entered, 18% of the variance was accounted for, ($F=1.490$, NS) without any single variable emerging as a significant predictor.

4) Composite dose delays

Multiple Regression

Using this measure as the dependent variable the proportion of the variance accounted for was 42.9%, ($F=2.001$, $p>.09$). Both Medication-specific self-efficacy measures emerged as significant predictors. Only these significant predictors are included in table 15.

Table 15. Multiple regression analysis for composite dose delays

Dependent variable	Independent variables	Beta	t	R Square	d.f.
Composite dose delays	Self-efficacy for adherence to specific medications	-.751	-2.412*	.429	24
	Self-efficacy for Medication-specific Problem Solving	.531	-2.191*		

Significance levels * $p<.05$ ** $p<.01$

Stepwise Regression

Both self-efficacy for adherence to specific medications, and self-efficacy for medication-specific problem solving were entered as the first two variables in a stepwise regression analysis, but no other significant predictors emerged.

Performing a stepwise regression with depression classified as a categorical measure, 14.5% of the variance was accounted for, ($F=1.084$, NS) with no significant predictors identified by the analysis.

H4. A positive relationship is predicted between perceived self-efficacy and adaptive coping strategies, such as acceptance, active coping, positive reframing, and planning.

Adaptive coping scores were obtained by summing the scores from the acceptance, active coping, positive reframing, and planning variables. A Pearson correlation was conducted using the GSES and adaptive coping variables. A modest correlation of 0.321 was obtained ($p<.05$). Further analysis with the individual variables, acceptance, active coping, positive reframing and planning revealed that only one variable, positive reframing, was significantly correlated with GSES (0.371, $p<.01$). Acceptance was not normally distributed so a Spearman's rho correlation coefficient was calculated for this variable. No significant correlations were obtained with acceptance, active coping, or planning.

-
- H5. An inverse relationship is predicted between perceived self-efficacy and maladaptive coping strategies, such as denial, behavioural disengagement, self-distraction, alcohol and substance use.**

Maladaptive coping scores were obtained by summing the scores from the denial, behavioural disengagement, and self-distraction variables. They were then recalculated to include alcohol and substance abuse. A similar analysis was conducted with the GSES and total maladaptive coping score, and a correlation of $-.306$ was obtained, ($p < .05$). Individual maladaptive coping strategies were also correlated separately with GSES. This showed that behavioural disengagement and GSES were correlated $-.333$, ($p < .05$), but neither denial nor self-distraction were correlated with GSES. A weak but statistically significant correlation ($.261$, $p < .05$) was obtained when alcohol and substance use was correlated with GSES.

- H6. Self-efficacy will account for a greater proportion of the variance than other Health Belief components of the Health Action Process Approach (interpersonal aspects of care, perceived susceptibility, perceived severity, intentions, supports and barriers, and subjective norms).**

The means for interpersonal aspects of care, perceived utility, perceived severity, perceived susceptibility, subjective norms, intentions, supports and barriers, and perceived self-efficacy were linearly transformed to a 0-100 scale and entered into

multiple and stepwise regressions using each of the four adherence measures as the dependent variable.

The number of items, score range, mean and standard deviations (transformed linearly to a 0-100 scale), and Cronbach's alpha reliability for each of the final subscale measures are presented in Table 2.

1) Global adherence to dose times,

When this measure was used as the dependent variable, 24% of the variance was accounted for ($F=1.530$, Sig.179). No component of the model emerged from the multiple regression as a statistically significant predictor of this measure of adherence, or indeed from a stepwise regression.

2) Global adherence to special instructions,

When global adherence to special instructions was substituted as the dependent variable in the multiple regression, 15.2% of the variance was accounted for, ($F=.807$ Sig .601) and no significant predictors were identified by this analysis or by a stepwise regression.

3) Composite dose omissions

Using composite dose omissions as the dependent variable, the components of the model accounted for 17.3% of the variance ($F=.992$ Sig .458) without any individual component emerging as a significant predictor. A stepwise regression was also performed but did not identify any significant predictors.

4) Composite dose delays

Using composite dose delays as the dependent variable in a multiple regression, the components of the model accounted for only 9.1% of the variance, ($F=.464$ Sig .874).

No single statistically significant predictor emerged from the multiple regression, or indeed, from a stepwise regression.

Additional Analyses

Further Spearman's rank correlations between the coping variables and the four measures of adherence were calculated, see Table 16. From this table it can be seen that denial coping was positively correlated with the composite measure of doses missed, (.396, $p>.01$). a weak correlation was also obtained between substance use and the global measure of adherence to dose times, (.296, $p>.05$) and, more robustly, with the measure of dose omissions, (.520, $p>.01$). Use of emotional support was negatively correlated with the composite measure of dose omissions, (.363 $p>.05$).

Table 16. Correlations between coping strategies and adherence measures

	Global adherence to dose times	Global adherence to special instructions	Composite dose omissions	Composite dose delays
Self-Distraction	.092	.067	.013	-.062
Active Coping	-.214	-.024	-.272	-.143
Denial	.018	.096	.396**	.073
Alcohol + Drug Use	.296*	.035	.520**	.227
Use of Emotional Support	.072	.272	-.363*	-.262
Behavioural Disengagement	.030	-.251	.102	-.090
Venting	.128	-.266	.121	.045
Positive Reframing	-.001	-.050	-.033	.081
Planning	-.232	-.172	.064	.051
Humour	.098	-.035	-.015	-.043
Acceptance	.110	-.224	-.068	.176
Religion	-.078	-.005	.151	.172
Adaptive Coping	-.092	-.131	-.091	.052
Maladaptive Coping	.083	.044	.209	-.092
Maladaptive Coping, (including substance use)	.141	.090	.343*	.031

*Significance levels * $p < .05$ ** $p < .01$*

Four stepwise regressions were also conducted using the four measures of adherence as dependent variables.

1) Global adherence to dose times,

When a stepwise regression was conducted using global adherence to dose times, the use of alcohol and drugs as a coping strategy accounted for 17.3% of the variance and was statistically significant as a predictor of this measure of adherence, $p > .05$, ($F=8.347$, Sig. .006).

2) Global adherence to special instructions,

The stepwise regression did not identify any coping strategy as a significant predictor of this measure.

3) Composite dose omissions

When a stepwise regression was conducted using the measure of composite dose omissions, the use of alcohol and drugs as a coping strategy accounted for 21.1% of the variance and was statistically significant as a predictor of this measure of adherence, $p > .05$, ($F=10.691$, Sig. .002).

4) Composite dose delays

The stepwise regression failed to identify any coping strategy as a significant predictor of this measure.

Summary of findings

H1. A positive relationship is predicted between perceived self-efficacy and adherence to combination drug therapies in HIV.

- For two out the four adherence measures (the global measures of adherence) there were no correlations with any of the self-efficacy measures.
- However, all three self-efficacy measures were negatively correlated with the measure of dose omissions.
- The measure of self-efficacy for adherence to specific medications was also negatively correlated with the composite measure of doses delayed.

H2. An inverse relationship is predicted between self-efficacy and depression.

- The Generalised Self-efficacy Scores and the HADS depression scores were negatively correlated. However, there is no data on the use of the HADS as a linear one. Using the HADS as a categorical measure, and conducting a one way Anova established significant differences between those in the non-clinical range, and those with possible psychiatric disorder. No significant differences in GSES scores between those with probable psychiatric disorder and the other two groups were observed.

H3. Irrespective of depression level, it is predicted that perceived self-efficacy will account for a significantly greater proportion of the variance in adherence to antiretroviral medications than other variables known to be associated with adherence such as age, substance use, AIDS diagnosis, and side-effects.

- Only three of the factors, (age, depression, and recreational drug use) identified from previous research as predictive of adherence were associated with the measures of adherence in this study.

Doses Omissions

- For two out of the four measures of adherence, (the global measures), no significant predictors emerged from regression equations.
- Recreational drug use, but not depression, age, or the experience of side-effects, was the only significant predictor of composite dose omissions to emerge from a multiple regression analysis.
- Once recreational drug use was controlled for, in a stepwise regression, self-efficacy for adherence to specific medications emerged as a significant predictor.

Dose Delays

- When the number of doses delayed was taken as the dependent variable, the only predictors were the two medication-specific self-efficacy measures, self-efficacy for adherence to specific medications and self-efficacy for medication-specific problem solving. These two measures accounted for 42.9% of the variance. Conducting an additional stepwise regression to control for medication-specific self-efficacy, did not lead to any other variables emerging as significant predictors.

H4. A positive relationship is predicted between perceived self-efficacy and adaptive coping strategies, such as acceptance, active coping, positive reframing, and planning.

- GSES was significantly associated with adaptive coping, although when the relationships with the individual components of adaptive coping were examined, significant correlations were only observed with positive reframing.

H5. An inverse relationship is predicted between perceived self-efficacy and maladaptive coping strategies, such as denial, behavioural disengagement, self-distraction, alcohol and substance use.

- GSES was negatively correlated with maladaptive coping. Further investigation of the relationship between GSES and individual elements of maladaptive coping found

no significant association with denial or self-distraction, but a significant correlation with behavioral disengagement (and also with substance abuse).

H6. Self-efficacy will account for a greater proportion of the variance than other Health Belief components of the Health Action Process Approach.

Entering the Health Belief components of the Health Action Process Approach into multiple regressions with the four adherence measures as dependent variables accounted for up to a quarter of the variance, but no element of the model emerged as a significant predictor from multiple or stepwise regressions.

4. Discussion

This section will provide a detailed analysis of this research and its contribution to the body of knowledge outlined in the introduction. It will be subdivided as follows:

- interpretation of the results in relation to previous research into adherence in HIV.
- interpretation of the results in relation to general adherence research,
- interpretation of the results in relation to the hypotheses,
- interpretation of the results in terms of the theories presented,
- methodological considerations,
- clinical and service implications,
- suggestions for further research,
- conclusions.

4.1 Interpretation of the results in relation to previous research into adherence in HIV.

High rates of adherence were reported across all adherence measures by this sample, although there was considerable variation between measures. Previous research has identified that people are normally accurate about non-adherence but tend to overestimate adherence. Research into adherence in other conditions suggests that the more specific the questions asked, the more accurate the information obtained. The findings from this study are consistent with this pattern. The levels of adherence reported when participants were asked global questions about their adherence were higher than those obtained by summing responses to questions about individual drugs, thereby forming composite measures.

In the current study, the greater the specificity of the adherence measure, the higher the rate of non-adherence reported. Since patients' reports of non-adherence are usually accurate, (Fletcher, 1989, cited in Myers & Midence, 1998), one can assume that these specific measures are more accurate than the global ones. Similarly, the strength of the association between the medication specific measures of self-efficacy and the composite measures of adherence lends further support to Bandura's contention about the specificity of self-efficacy judgements.

Different patterns were obtained for the measure of dose omissions and dose delays which suggests that the processes involved might be subtly different, although clearly related.

Overall, 42.3% of this sample considered themselves excellent, and half, good, at taking their drugs as prescribed. More detailed questions elicited information which suggests a discrepancy between the self perception and the reality of their medication taking behaviour. When asked specifically about dose timing, 25% reported that they sometimes took doses late, while 10% usually or always did so. This indicates that a third of this sample struggle with this aspect of adherence. When asked about dose delays for individual drugs, 36.5% had taken a dose late on one or more days during the previous week.

Fewer people had missed doses altogether, although just over a quarter reported that they had missed a dose on at least one day during the previous week.

Almost half the sample said that they never took their drugs without adhering to the special instructions. 29.9% said they sometimes, usually or always, neglected to follow the special instructions.

Consistent with the findings from previous research, this study found age, depression, self-efficacy and substance use were associated with adherence, although only substance use and self-efficacy emerged as significant predictors in regression analyses.

No relationship between side-effects and adherence was observed. This may be because medical management of side-effects within this service keeps side-effects to a minimum. The presence or absence of side-effects may be too simplistic a measure, and it may be the type of side effect that is important. Certainly, anaemia, leukopenia and diarrhoea are known to affect adherence. Alternatively, it may be the level of side-effects experienced. People may be able to tolerate side-effects and their impact on their lives up to a certain threshold, after which adherence declines.

This sample size was insufficient to test whether sex or race was related to adherence in this study.

This sample had had quite some time to become accustomed to their HIV diagnoses and their treatments. Previous research suggests that most difficulties with adherence are experienced when commencing treatment, with people gradually incorporating their medications into their routines over the first few months. However, Gallant & Block's research, (1988) suggests that there may be a plateau effect with the number of drug holidays increasing after two years. It may be that accidental, passive non-adherence is greater at the start of treatment, while deliberate, active non-adherence is more prevalent later on, although only one person in this sample reported taking drug holidays.

Unlike previous research, (Singh et al. 1996) this study did not find a positive relationship between adaptive coping and adherence.

4.2 Interpretation of the results in relation to general adherence research

The finding that active coping was not associated with adherence is consistent with the results from the MOS study, (Sherbourne et al. 1992). Similarly the relationship between denial coping and adherence observed in this study has been identified in other studies, (Croog, Shapiro, & Levine, 1971, cited in Sherbourne, 1992).

4.3 Interpretation of the results in relation to the hypotheses,

H1. A positive relationship is predicted between perceived self-efficacy and adherence to combination drug therapies in HIV.

Both the general and the two medication specific measures of self-efficacy were related to adherence measured by dose omissions. Self-efficacy for adherence to specific medications was also related to adherence measured in terms of doses delayed. These findings provide support for the thesis that perceived self-efficacy and adherence are related although the relationship appears to be stronger when considering dose omissions than dose delays.

H2. An inverse relationship is predicted between self-efficacy and depression.

A strong negative correlation was observed between the general measure of self-efficacy and depression. As there is no data on its use as a linear measure, further analysis was conducted as a categorical measure which established no significant differences in GSES scores between the clinical and non clinical groups. These findings suggest that while depression and a lack of perceived self-efficacy may be related, the relationship is not a simple one, and depression and self-efficacy are distinct phenomena. Depression is clearly more than just an absence of self-efficacy.

H3. Irrespective of depression level, it is predicted that perceived self-efficacy will account for a significantly greater proportion of the variance in adherence to antiretroviral medications than other variables known to be associated with adherence such as age, substance use, depression, AIDS diagnosis, and side-effects.

Contrary to the findings from other studies, depression did not emerge from regression equations as a predictor of any of the four measures of adherence, although it was correlationally related to the composite measure of dose omissions.

Recreational drug use was the only predictor of dose omissions identified by multiple regression. However, controlling for drug use in a stepwise regression allowed self-efficacy for adherence to specific medications to predict a further 12.7% of the variance. These findings demonstrate that for this sample, recreational drug use is the most crucial factor in predicting non-adherence in terms of missed doses.

Nevertheless, once this is taken into account, perceived self efficacy for adherence to specific medications emerges as a significant predictor. The correlation between depression and adherence suggests that drug use and self-efficacy may be masking the contribution made by depression.

The picture for dose delays was clearer in that both forms of medication specific self-efficacy, (but not drug use) were the only predictors to emerge from multiple or stepwise regression analyses.

Taken together these findings provide some support for this hypothesis although the evidence is stronger for dose delays than for dose omissions, for which recreational drug use is the most important factor.

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- H4. A positive relationship is predicted between perceived self-efficacy and adaptive coping strategies, such as acceptance, active coping, positive reframing, and planning.**

It would appear that general self-efficacy as measured by the GSES, and adaptive coping are indeed associated, although the effect appears to be accounted for by the relationship between GSES and positive reframing.

- H5. An inverse relationship is predicted between perceived self-efficacy and maladaptive coping strategies, such as denial, behavioural disengagement, self-distraction, alcohol and substance use.**

GSES is inversely related to the use of maladaptive coping strategies, although this may be a function of the relationship between GSES and behavioural disengagement, since no significant relationship with denial or self-distraction were observed.

- H6. Self-efficacy will account for a greater proportion of the variance than other Health Belief components of the Health Action Process Approach (interpersonal aspects of care, perceived susceptibility, perceived severity, intentions, supports and barriers, and subjective norms).**

The Health Belief components of the Health Action Process Approach did not account for more than a quarter of the variance, whichever measure of adherence was used. This was not sufficient for any single component to emerge as a predictor. Such findings do not provide support for this model.

4.3 Interpretation of the results in terms of the theoretical background of the study.

Self-Efficacy

Perceived Self-Efficacy and Adherence

Self-efficacy may mediate adherence through its effect on dealing with setback. Forgetting a dose, (whether or not one remembers before one is due to take the next dose) may have some similarities to the experience of relapse / abstinence violation for drinkers or smokers, a process studied by Marlatt & Gordon, (Marlatt & Gordon, 1980, cited in O'Leary, 1985). These authors suggest that people who relapse attribute their slip to personal shortcomings which decreases their perceived self-efficacy for remaining abstinent. Self-efficacy may buffer the experience of setback, more generally. Certainly, research with smokers has identified that post intervention self-efficacy is the best predictor of smoking cessation

Perceived Self-Efficacy and Mood

The findings from this study provide some correlational support for Bandura's (1997) proposition that perceived self-efficacy is inversely related to depression, although significant differences were not confirmed by a one way Anova.

The development of the new combination drug therapies offers HIV positive people a source of perceived control over the disease. It is possible, as Bandura, (1982) has argued, that a situation of perceived control is potentially distressing for those whose self-efficacy about their ability to use it is low. The option of combination therapy may then be a source of distress for those with low self-efficacy.

Perceived Self-Efficacy and Coping

Perceived self-efficacy and choice of coping strategy were related in this sample. High levels of perceived self-efficacy were associated with adaptive coping and low levels with maladaptive coping. However, it would appear from these results that perceived self-efficacy, or its lack, is more strongly associated with some strategies than with others. In particular, it was positively associated with positive reframing, and negatively correlated with behavioural disengagement. This is consistent with the prediction (Bandura, 1997, O'Leary, 1985) that lack of efficacy in relation to a particular goal, leads to the abandonment of efforts to achieve it.

It may be that self-efficacy is particularly important in situations of uncertainty. One of the few consistencies in the experience of people with HIV has been uncertainty about the disease, its prognosis and its treatment. Even now, the situation is constantly changing. The comparison between receiving an HIV diagnosis with

receiving a diagnosis of diabetes illustrates this difference. People with diabetes know roughly what they can expect and what influences the outcome. Much less is known about HIV and in these circumstances perceived self-efficacy may be the more important.

It is people who are already socially disadvantaged and vulnerable, (through race, drug use, abuse histories, sexual orientation) who are at greatest risk of HIV. For some, the experience of discrimination and adversity will have reduced their general sense of self-efficacy (although it is interesting that the mean GSES score reported by this sample was not significantly different from Schwarzer's German sample, 1992).

Health Action Process Approach

The findings of this study suggest that perceived-self efficacy for adherence to specific medications may be an important predictor of adherence, which would need to be incorporated in any model. However, these results do not provide support for the Health Action Process Approach, the model which gives greatest weight to the influence of self-efficacy. At its most successful, in predicting the global measure of adherence to dose times, components of the Health Action Process Approach accounted for 24% of the variance which is roughly comparable to the average proportion of the variance accounted for by components of the Health Belief Model, according to the meta-analysis conducted by Zimmerman & Vernberg, (1994, cited in Horne & Weinman, 1998).

Coping

The strongest correlation between coping strategy and adherence was the positive relationship between alcohol and drug use, and the composite measure of doses missed. This corroborates the earlier finding linking recreational drug use with non-adherence. A positive relationship between denial and the composite measure of dose omissions was also obtained. This may reflect an aspect of avoidance coping which has been found to be related to adherence in other studies, (Sherbourne et al. 1992).

It is interesting that the use of emotional support is negatively correlated with dose omissions.

4.4 Methodological considerations

A number of methodological issues need to be taken into consideration when interpreting these results.

Design

Clearly, cross-sectional research cannot establish the direction of causality, only the existence of relationships between the dependent and independent variables, which may be attributable to the presence of a third unexamined variable. It is also possible that as Borkovec, (1978, cited in Eastman & Marzillier, 1984) Eastman & Marzillier (1984) have argued, that self-efficacy represents more or less accurate judgements of people's past adherence behaviour. Adherence is better conceived of as a process requiring longitudinal study

Measures

The questionnaire developed for this study was both long and repetitive, especially for those on many drugs. This was due to the attempt to achieve methodological rigour. Whilst every effort was made to keep the questionnaire concise, this may have deterred some from participation. Equally, participants may have become fatigued and spent less time considering the accuracy of their responses.

This is a new and complex area of research, and as yet there is an absence of established methodology for measuring adherence, health beliefs, or self-efficacy in people with HIV. All the measures were self-report measures and there was no corroboration with objective measures. It is likely, therefore, that adherence has been

overestimated and possible that social desirability factors influenced responses to all measures.

Treatment Adherence Measures

Most crucially, no objective measures of adherence are available.

Mood

There does not appear to be a scale for measuring the extent of depression in people with physical conditions, let alone one standardised on an HIV positive population.

Coping

Given the average length of time since diagnosis, the situational version of the COPE may have been inappropriate. Use of this measure also precluded investigation of the relationship between avoidant coping and adherence in this population, a relationship which has been established in other chronic conditions, (Sherbourne et al. 1992).

Research into coping in HIV positive populations has used a variety of coping measures: the Dealing with Illness Coping Measure (Fukunishi et al. 1996), the HIV Coping List, (Mulder et al. 1995), or the Ways of Coping Revised Checklist, (Folkman & Lazarus, 1980, 1985, Sharts-Hopko et al. 1996) which hinders comparison across studies.

Coyne & Gottlieb (1996) identify various drawbacks to the use of standardised coping checklists. Amongst other issues they suggest that many habitual coping responses become automatic and may not therefore be recognised as coping strategies by respondents.

Generalised Self-Efficacy Scale

All the normative data for this measure has been collected from German samples and may not generalise to other populations.

HIV specific Health Beliefs

Reliability and validity have not been established for this questionnaire in its adapted form, nor has it been standardised on an HIV positive population. It could be argued that it is not a valid measure of the Health Action Process Approach, as it does not directly assess social support but confines itself to the measurement of subjective norms. Social support may be a powerful determinant of adherence in HIV. It is worth noting, on this point, that the use of emotional support was positively correlated with adherence, (as measured by dose omissions).

Sample

The small sample size means conclusions must be drawn with caution. In addition the self-selecting nature of the sample brings dangers of bias. However, the most serious methodological weakness of the study concerns the recruitment of the sample. The design approved by the ethics committee entailed the initial approach to patients being made by the researcher. However, this approval was necessarily subject to the consent of the consultants with clinical responsibility for each patient. One consultant insisted that the initial approach be made by doctors. In order to ensure that none of her patients were inadvertently approached, and to ensure consistency, all approaches to patients on the St Bartholomew's site were made by doctors during clinic

appointments. This reduced the numbers available for recruitment by excluding the large numbers of patients waiting to see other health professionals.

This clearly introduces a potential source of selection bias into the system.

When these concerns were expressed to one of the registrars, he remarked, "*There's a selection bias at work, we tend to send only the adherent, uncomplicated people your way.*" This suggests that there was indeed a selection bias in operation for at least one doctor, although physician estimates of adherence are generally unreliable, (Ley, 1988). It suggests that those obviously struggling with adherence and open with their doctor were not asked to participate. This clearly casts doubt on the representative nature of the sample. It would seem reasonable to assume that those who agree to participate in research are likely to be more adherent than those who decline. Including another source of bias into the process is likely to have resulted in a sample further skewed towards adherence.

Additionally, those with severe physical or psychological illnesses were excluded from the study, and it is impossible to know how this affected the results. In other research, poor health is associated with greater adherence, although in this sample poorer health status, as indicated by the presence of an AIDS diagnosis was correlated with more dose omissions.

It is therefore possible that the trends apparent in these results would be more pronounced in a more representative sample, although this could only be established by further research.

It is also possible that despite assurances of confidentiality, participants were concerned that information would be relayed to their doctors. The fact that initial approaches were made by doctors may have served to blur the distinction between the

researcher and the clinicians. Concerns about confidentiality were certainly expressed. A number of African women declined to take part, once they realised participation involved signing a consent form, even though this would be kept separate from the questionnaire which was, itself, anonymous.

4.6 Clinical and service implications

One of the more important findings of this study is the higher rates of non-adherence obtained from drug specific self-report measures compared with global measures. This certainly suggests that reliance on responses to global questions may overestimate adherence.

The most effective strategy might be to incorporate more detailed adherence monitoring into standard care, with patients routinely asked to complete brief adherence measures about dose omissions, dose delays, and adherence to special instructions while they wait for appointments. This would provide an opportunity for discussion of any problems with their doctor. Monitoring self-reported adherence in the way that CD4 counts and viral load are routinely monitored would allow patients to receive direct feedback on the relationship between the two (and reinforcement). Conversely, it might also prevent those who do not respond to medication being labelled as nonadherent.

A process more sensitive to detecting adherence difficulties would also allow for other forms of intervention. This is surely classical clinical psychology territory. Psychologists already have expertise in working with people to change their habits, (admittedly, normally to relinquish rather than reinforce them, but it is part of the same process). Health psychologists have well established roles in working with

people with diabetes to increase their adherence to diet and exercise regimes. This knowledge base could be applied to working with adherence in HIV. In many areas this is already happening, although rarely in an explicit fashion which allows for monitoring of the intervention.

Clearly, further research is needed to clarify the role of self-efficacy. Should it prove to be as significant as the results of this study suggest, it is easily monitored and, moreover, amenable to intervention, (Gattuso et al. 1992).

Since self-efficacy expectations are formed partly on the basis of perceptions about past behaviour, it is important that people do not underestimate their previous adherence. It is therefore important that people begin combination therapy with realistic expectations and are prepared for the occasional lapse. Catastrophic interpretations of the meaning of forgetting a dose may dramatically reduce self-efficacy and thus adversely effect adherence.

Given the relationship between recreational drug use and dose omissions, and the proportion of this sample using drugs, it would seem wise to ask patients about their drug use before they start combination therapy, so patient and clinician can discuss strategies for minimising the risk of dose omissions. It may be that alarms would prove particularly useful at such times. Some regimes are more forgiving of lapses than others, so it might be prudent to select one of them for people whose recreational drug use places them at risk of impaired adherence.

4.7 Suggestions for further research

Further studies are needed to confirm the causal relationship between perceived self-efficacy and adherence using prospective longitudinal designs in which a range of adherence measures are used. Measures of both depression and self-efficacy are needed to ascertain which is the crucial variable.

Ideally, in order to minimise sampling issues, standardised adherence monitoring needs to be incorporated into the routine care of HIV positive patients. This would permit the tracking of longitudinal fluctuations in adherence.

Considering that group interventions for people with HIV are now well established, it ought to be possible to integrate components targeting self-efficacy acquisition into existing interventions, such as Coping Effectiveness Training. This would allow for the assessment of the effects of Coping Effectiveness Training incorporating self-efficacy acquisition on adherence, relative to standard Coping Effectiveness Training or routine care.

Research could establish whether adherence to medication, and other forms of problem focused coping are associated with high levels of general and specific self-efficacy.

In addition to the health benefits for individual patients, this could increase our understanding of adherence in its widest sense, and might help those with conditions other than HIV.

To facilitate this process, further work is needed developing measures standardised on patients with chronic illnesses, and preferably on HIV positive populations. This would allow for further testing and refinement of the models used

to predict adherence which have not proved especially powerful in this study, or others, so far.

It may be that current models are too simplistic and that frameworks need to be developed integrating coping theory with existing models. The relationship between perceived self-efficacy and coping needs further investigation.

4.8 Conclusions

Adherence research is hampered by the lack of consensus as to what constitutes adherence, let alone the best method of measurement. Co-operation between all groups is needed to foster progress in this area, multidisciplinary collaboration and the closer involvement of patients is needed to address the problems of non-adherence. It is ethically indefensible to deny treatment to groups or individuals on the basis of presumptions about their capacity to adhere. Clinical energies would be better spent fostering adherence in those who are struggling and supporting those who maintain high adherence levels. Clinical psychologists can support this process by offering interventions to treat depression, and teaching harm minimisation strategies to those engaging in recreational drug use. These are obvious places to start, but further investigation of the predictors of non-adherence is needed, and low self-efficacy may merit special attention.

The findings of this study suggest that self-efficacy is related to adherence although the direction of causality remains to be established. Clearly, further research is needed to clarify the role of self-efficacy. Should it prove to be as significant as the results of this study imply, it is quickly and easily assessed and, moreover, amenable to intervention.

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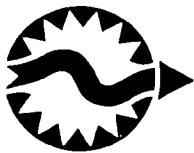
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East London and The City **HEALTH AUTHORITY**

Ms Pippa Stallworthy
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Andrews Unit
King George V Block
St Bartholomew's Hospital
London EC1A 7BE

Our ref: MS/SK/P99006

26th February 1999

Dear Ms Stallworthy

Re: P/99/006 – Perceived self-efficacy and adherence to antiretroviral therapy in HIV.

I acknowledge receipt of your informative response dated 15th February 1999, to my earlier concern.

I note the points you make and that now you will be conducting a pill-count at "time 2". Therefore, I am happy to approve your study under Chairman's action to be noted at future meeting of the Committee.

Please note the following conditions to the approval:

1. The Committee's approval is for the length of time specified in your application. If you expect your project to take longer to complete (i.e. collection of data), a letter from the principal investigator to the Chairman will be required to further extend the research. This will help the Committee to maintain comprehensive records.
2. Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee or Chairman's approval.
3. The Committee should be notified immediately of any serious adverse events or if the study is terminated prematurely.
4. You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, such as extra work for laboratories.
5. You must ensure that, where appropriate, nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

Chairman: Professor Frances Heidensohn

81-91 Commercial Road · London E1 1RD · Tel: 0171 655 6600 · Fax: 0171 655 6666

NHS


6. The Committee should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

I should be grateful if you would inform all concerned with the study of the above decision.

Your application has been approved on the understanding that you comply with Good Clinical Practice and that all raw data is retained and available for inspection for 15 years.

Please quote the above study number in any future related correspondence.

Yours sincerely


PROFESSOR M SWASH MD FRCP FRCPATH
Chairman
ELCHA Research Ethics Committee

Taking Your HIV Medications

Information Sheet

We would like to invite you to take part in a research study which we think may be important. This information sheet tells you about it. We are interested in looking at the factors which make taking antiretroviral drugs difficult. We hope that the information provided will help us to devise ways to make taking medication easier for people.

This research involves completing a written questionnaire which should take about 30 minutes, maybe more if you are taking many different drugs. If you are happy for us to do so, we will contact you in one months time to ask you to fill in part of the questionnaire a second time. Whether or not you take part is entirely your choice, and would not affect your treatment in any way.

Please feel free to ask any questions you want to about the research, and we will try our best to answer them. We can be contacted by telephone at the Andrewes Unit on 0171 601 7827.

Please try to answer all the questions that are relevant to the treatments you are taking, as the more questions you can answer the more helpful it is.

We would like to assure you that all information we obtain will remain strictly confidential. If you wish to fill in this form only once, this questionnaire is completely anonymous. If you are able to help us by filling in the questionnaire in one months time, we will ask you to give your clinic number. We would ask you to complete the questionnaire when you returned to the clinic for another appointment, or would post the questionnaire to you with a stamped addressed envelope. The information will still remain confidential to the research team and will be kept separate from your medical notes. If you decide not to be in the study, or drop out, this will not put at risk your ordinary medical care.

General information on patients rights regarding participation in research studies may be obtained from your local Community Health Council.

Please return the completed questionnaire in the sealed envelope provided.

Thank you very much for taking the time to complete the questionnaire.

Dr Barbara Hedge
Consultant Clinical Psychologist

Pippa Stallworthy
Clinical Psychologist in training

WRITTEN CONSENT FORM:**Perceived Self-Efficacy and Adherence to medication in HIV****REC Number:****Name of Patient/Volunteer (Block Capitals):****Address:**

- The study organisers have invited me to take part in this research. ☐
- I understand what is in the leaflet about the research. I have a copy of the leaflet to keep. ☐
- I have had the chance to talk and ask questions about the study. ☐
- I know that the local East London and The City Health Authority Research Ethics Committee has seen and agreed to this study. ☐
- I understand that personal information is strictly confidential: I know the only people who may see information about my part in the study are the research team or an official representative of the organisation which funded the research. ☐
- I freely consent to be a subject in the study. No-one has put pressure on me. ☐
- I know that I can stop taking part in the study at any time. ☐
- I know if I do not take part I will still be able to have my normal treatment. ☐
- I know that if there are any problems, I can contact:

Ms Pippa Stallworthy.....

Tel. No. 0171 601 7827..... Bleep No./Ext.

Patient's/Volunteer's: Signature

Witness's Name

Witness's Signature:

Date

The following should be signed by the Clinician/Investigator responsible for obtaining consent

As the Clinician/Investigator responsible for this research or a designated deputy, I confirm that I have explained to the patient/volunteer named above the nature and purpose of the research to be undertaken.

Clinician's Name:

Clinician's Signature: Date:

This questionnaire contained identical sets of questions for five drugs. In the interests of brevity, only the questions for the first drug have been presented here. Obviously, participants' questionnaires included the full set of questions for five drugs.

Taking Your HIV Medications

We would like some general information about you, this questionnaire is confidential, so we do not need your name, but if you are willing to participate in the second part of this study, please write your

Clinic number

How old are you?.....

Are you male ☐ or female ☐ (please tick)

How would you describe your cultural background? (please tick)

White: Eng/Scot/ Welsh	<input type="checkbox"/>	European	<input type="checkbox"/>	Greek	<input type="checkbox"/>
Greek Cypriot	<input type="checkbox"/>	Irish	<input type="checkbox"/>	Turkish	<input type="checkbox"/>
Turkish Cypriot	<input type="checkbox"/>	Orthodox Jewish	<input type="checkbox"/>	Jewish	<input type="checkbox"/>
Black Caribbean	<input type="checkbox"/>	Black African	<input type="checkbox"/>	Black (UK)	<input type="checkbox"/>
Black Somali	<input type="checkbox"/>	Black Other	<input type="checkbox"/>	Tamil	<input type="checkbox"/>
Indian	<input type="checkbox"/>	Sri Lankan	<input type="checkbox"/>	Chinese	<input type="checkbox"/>
Pakistani	<input type="checkbox"/>	Bangladeshi	<input type="checkbox"/>	Kurdish	<input type="checkbox"/>
Vietnamese	<input type="checkbox"/>	Traveller	<input type="checkbox"/>	Arab	<input type="checkbox"/>

Any other ethnic group (please specify).....

Which country were you born in?.....

What is your first language?.....

Do you have a main regular partner? Yes ☐ No ☐

If yes, how long have you been in this relationship?.....(years/ months)

Generally speaking, who do you have sex with? (please tick one of the following)

Men ☐ Women ☐ Men and Women ☐

Who do you live with? (please tick)

Alone	<input type="checkbox"/>	With partner and child/children	<input type="checkbox"/>
With partner	<input type="checkbox"/>	With child/children	<input type="checkbox"/>
With friend(s)	<input type="checkbox"/>	Other (please specify)	
With parents	<input type="checkbox"/>	

If you know your latest blood test results:

What was your last CD4 count (T cell count)?..... When was this?.....

What was your last viral load count?.....When was this?.....

When did you find out you were HIV positive?.....(month and year)

Have you got an AIDS diagnosis? (please tick) Yes ☐ No ☐

When were you given this?.....(month and year)

How much alcohol do you generally drink each week?.....Units
(1 Unit = 1 measure of spirit or 1 glass of wine or 1/2 pint of lager)

Please describe.....

Please list any non-prescription / recreational drugs you use, and how often you use them

Drug	How often used (per day, week, month)

Please fill in all the following questions in relation to the combination therapy / anti-retroviral drugs you are taking now. Please tick your response

How good do you think you are at taking drugs as prescribed?

- Excellent []
- Good []
- Reasonable []
- Poor []
- Disastrous []

Do you ever change the times of taking your drugs?

- Always []
- Usually []
- Sometimes []
- Occasionally []
- Never []

Do you ever stop taking the drugs for any reason, eg. drug holidays?

- Often []
- Occasionally []
- Never []

Do you ever change the dose of your drug?

- Always []
- Usually []
- Sometimes []
- Occasionally []
- Never []

Please say how long you were off drugs the last time you did this.

.....
.....

Which drugs did you stop taking?

.....
.....

Do you ever take the drugs without adhering to the prescribed regime? (eg. with / without food)

- Always []
- Usually []
- Sometimes []
- Occasionally []
- Never []

Which of the following drugs are you taking now?

Please tick all the drugs which you are currently taking, noting when you started taking them, and any side effects you are experiencing.

Drug	tick if taking now	Month and year you started taking drug	Side effects I think it's giving me
AZT (Zidovudine)			
ddi (Didanosine)			
ddc (Zalcitabine)			
d4T (Stavudine)			
3TC (Lamivudine)			
nelfinavir (Viracept)			
ritonavir (Norvir)			
saquinavir (Invirase)			
indinavir (Crixivan)			
nevirapine (Viramune)			
delavirdine			
dmp			
1592089 (Abacavir)			
<i>PCP prophylaxis</i>			
bactrim / septr (sulfa-trimethoprim)			
dapsone			
aerosolised pentamidine			

For each of the drugs you have ticked please fill in one of the following sheets. If you are taking only one of these drugs you need fill in only one drug sheet. Most people will be taking one, two, three or four of these antiretroviral drugs; those that are thought to be the most suitable combination for you. You may also be taking medication to prevent PCP, please fill in a sheet for this too.

Most people with HIV have many different pills to take at different times of the day, and many find it hard to remember all of them. We need to understand how people with HIV are really doing with their pills. Please tell us what you are **actually** doing. Don't worry about telling us that you don't take all your pills. we need to know what is really happening, not what you think we want to hear.

Please write here the name of the first drug you have ticked.....

For this drug please answer the following questions

How many times a day do you take it? _____ times

How many times a day are you supposed to take it? _____ times

How many times did you take the drug yesterday? _____ times

Did you miss any doses yesterday? Yes [] No []

How many? _____ times

How many days did you miss a dose of the drug last week? _____ times during the past week

Are there any special instructions which come with this drug? (please specify)

.....

.....

.....

Many people find it difficult to follow special instructions about taking their drugs

How often do you keep exactly to these instructions?

Always	[]
Usually	[]
About half the time	[]
Occasionally	[]
Never	[]

Please tell me **exactly** how you take the drug by ticking **all** the boxes which best describe how you take it:

I always take it

On an empty stomach	[]
With water	[]
Without food	[]
With a snack	[]
With a full meal	[]
At least 2 hours before eating	[]
At least 2 hours after eating	[]

I usually take it

On an empty stomach	[]
With water	[]
Without food	[]
With a snack	[]
With a full meal	[]
At least 2 hours before eating	[]
At least 2 hours after eating	[]

What happened the last time your routine for taking this drug fell apart? Did you:

Miss a dose []

Take a dose late []

Not follow special instructions []

Other.....

.....

.....

When was the last time this happened?.....

(this can be as far back as you remember - it does not have to be in the past week)

Why did this happen? (please tick)

Slept/fell asleep	<input type="checkbox"/>	Had too much alcohol, or	<input type="checkbox"/>
Change of eating routine	<input type="checkbox"/>	recreational drugs	
Did not want to take medication		In hurry, busy schedule,	<input type="checkbox"/>
in front of other people	<input type="checkbox"/>	rushing around	
Out of house/away from meds	<input type="checkbox"/>	Don't know	<input type="checkbox"/>
Forgot	<input type="checkbox"/>	Drug required refrigeration	<input type="checkbox"/>
Sick (NOT side effects)/in hospital	<input type="checkbox"/>	Instructions too difficult	<input type="checkbox"/>
Side effects/bad taste	<input type="checkbox"/>	(e.g. take with food, fluid etc.)	
Distracted by something	<input type="checkbox"/>	Ran out of medications	<input type="checkbox"/>
Other, (please specify).....			

If you missed a dose, or took it late, how did you realise that you had not taken your drug?

Someone else reminded you	<input type="checkbox"/>	Just remembered on own at a later time	<input type="checkbox"/>
Timer or beeper reminded you	<input type="checkbox"/>	Had leftover pills in planner/bottle	<input type="checkbox"/>
Other scheduled events reminded you (e.g. taking another medication, mealtime)			

How often does something like this happen?

Every day	<input type="checkbox"/>		
Nearly every day	<input type="checkbox"/>	2-3 times a month	<input type="checkbox"/>
3 or 4 times a week	<input type="checkbox"/>	Once a month	<input type="checkbox"/>
1 or 2 times a week	<input type="checkbox"/>	Less than once a month	<input type="checkbox"/>

How many times has this happened during the past week? _____ times

How many times have you taken a dose **late** during the past week? _____ times

Taking this drug the way you do, how much benefit do you think you are getting from it?

All possible benefit	<input type="checkbox"/>	Some benefit	<input type="checkbox"/>
Most of the benefit	<input type="checkbox"/>	Not much benefit	<input type="checkbox"/>
Enough to make it worth taking <input type="checkbox"/>			

On a scale of 1-5 where 1 is not sure at all and 5 is very sure, in the next month, how sure are you that you will be able to take this medication as directed?

1	2	3	4	5
Not sure at all	Unsure	Neither sure nor unsure	Sure	Very sure

How sure are you that you will be able to deal with any problems associated with taking your medications?

1	2	3	4	5
Not sure at all	Unsure	Neither sure nor unsure	Sure	Very sure

Please read each item and place a tick in the box opposite the reply that comes closest to how you have been feeling in the past month: Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

	Most of the time []	A lot of the time []	Occasionally []	Not at all []
1. I feel tense/ wound up.				
	Definitely as much []	Not quite as much []	Only a little []	Hardly at all []
2. I still enjoy things I used to				
	Very definitely and quite badly []	Not too badly []	Little, doesn't worry me []	Not at all []
3. I get a sort of frightened feeling as if something awful is about to happen.				
	As much as I ever could []	Not quite so much now []	Definitely not so much []	Not at all []
4. I can laugh and see the funny side of things:				
	A great deal of the time []	A lot of the time []	From time to time []	Only occasionally []
5. Worrying thoughts go through my mind:				
	Not at all []	Not often []	Sometimes []	Most of the time []
6. I feel cheerful:				
	Definitely []	Usually []	Not often []	Not at all []
7. I can sit at ease and feel relaxed:				
	Nearly all of the time []	Very often []	Sometimes []	Not at all []
8. I feel as if I am slowed down:				
	Nearly all of the time []	Very often []	Sometimes []	Not at all []
9. I get a frightened feeling like butterflies in my stomach:				
	Definitely []	I don't take as much care as I should []	I may not take quite as much care []	I take just as much care as ever []
10. I have lost interest in my appearance:				
	Very much indeed []	Quite a lot []	Not very much []	Not at all []
11. I feel restless as if I have to be on the move.				
	As much as I ever did []	Rather less than I used to []	Definitely less than I used to []	Hardly at all []
12. I look forward with enjoyment to things:				

13. I get sudden feelings of panic:	Very often indeed []	Quite often []	Not very often []	Not at all []
14. I can enjoy a good book, radio or TV programme:	Often []	Sometimes []	Not often []	Very seldom []

This set of items deals with the ways you've been coping with the stress in your life since you found out you were HIV positive. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know *to what extent* you've been doing what the item says. How *much* or how *frequently*. Don't answer on the basis of whether it seems to be *working* or not - just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from these others. Make your answers as true FOR YOU as you can.

On a scale of 1-4 where 1 is I haven't been doing this at all, 2 is I've been doing this a little bit, 3 is I've been doing this a medium amount, and 4 is I've been doing this a lot, please answer the following questions.

	I haven't been doing this at all 1	I've been doing this a little bit 2	I've been doing this a medium amount 3	I've been doing this a lot 4
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation.	1	2	3	4
3. I've been saying to myself, "this isn't real".	1	2	3	4
4. I've been using alcohol or drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
11. I've been trying to see it in a different light,	1	2	3	4

to make it seem more positive.

12. I've been trying to come up with a strategy about what to do.	1	2	3	4
13. I've been getting comfort and understanding from someone.	1	2	3	4
14. I've been giving up the attempt to cope.	1	2	3	4
15. I've been looking for something good in what is happening.	1	2	3	4
16. I've been making jokes about it.	1	2	3	4
17. I've been doing something to think about it less, such as going to movies, watching TV, reading daydreaming, sleeping or shopping.	1	2	3	4
18. I've been accepting the reality of the fact that it has happened.	1	2	3	4
19. I've been expressing my negative feelings.	1	2	3	4
20. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
21. I've been learning to live with it.	1	2	3	4
22. I've been thinking hard about what steps to take.	1	2	3	4
23. I've been praying or meditating.	1	2	3	4
24. I've been making fun of the situation.	1	2	3	4

On a scale of 1-4 where 1 is not at all true, and 4 is exactly true, please answer the following questions.

	Not at all true	Barely true	Moderately true	Exactly true
1. I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2. If someone opposes me, I can find means and ways to get what I want.	1	2	3	4
3. It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4. I am confident that I could deal efficiently with unexpected events.	1	2	3	4

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
6. I can solve most problems if I invest the necessary effort.	1	2	3	4
7. I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8. When I am confronted with a problem, I can usually think of something to do.	1	2	3	4
9. If I am in a bind, I can usually think of something to do.	1	2	3	4
10. No matter what comes my way, I'm usually able to handle it.	1	2	3	4

On a scale of 1-5 where 1 is strongly disagree and 5 is strongly agree, please answer the following questions.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The doctors and other health professionals sometimes ignore what I tell them.	1	2	3	4	5
2. The doctors and other health professionals listen carefully to what I have to say.	1	2	3	4	5
3. The doctors and other health professionals answer all my questions.	1	2	3	4	5
4. Sometimes the doctors and other health professionals use medical terms without explaining what they mean.	1	2	3	4	5
5. I trust that the doctors and other health professionals have my best interests at heart.	1	2	3	4	5
6. The doctors and other health professionals act like I'm wasting their time.	1	2	3	4	5
7. The doctors and other health professionals treat me in a very friendly and courteous manner.	1	2	3	4	5

8. The doctors and other health professionals show little concern for me.	1	2	3	4	5
9. The doctors do not really know what the drug is doing to me (I feel like a guinea pig).	1	2	3	4	5
10. If I take my drugs I am less likely to get ill.	1	2	3	4	5
11. My drugs help overcome the tiredness associated with having AIDS.	1	2	3	4	5
12. I think I will be more closely monitored at the clinic if I take my drugs.	1	2	3	4	5
13. Following my treatment plan will help me to be healthy.	1	2	3	4	5
14. I'll be just as healthy if I avoid my treatment plan.	1	2	3	4	5
15. I believe that my treatment plan will help to prevent my getting HIV related symptoms.	1	2	3	4	5
16. It's hard to believe my treatment plan will help me.	1	2	3	4	5
17. I think my treatment plan can buy me time while a cure is developed.	1	2	3	4	5
18. If I do not take my drugs, I will not be able to fight AIDS on my own.	1	2	3	4	5
19. Taking my drugs will help reduce worry that I have about my future health.	1	2	3	4	5
20. I believe that not taking care of infections will lead to serious consequences in the future.	1	2	3	4	5
21. I believe that my medications will manage my HIV.	1	2	3	4	5
22. My treatment plan is too much trouble for what I get out of it.	1	2	3	4	5
23. The benefits of my treatment plan outweigh any difficulty I might have in following it.	1	2	3	4	5
24. The side effects of my drugs outweigh their benefits.	1	2	3	4	5
25. Following my treatment plan is better for me than not following my treatment plan.	1	2	3	4	5

26. I believe that my medications will help prevent complications related to HIV.	1	2	3	4	5
27. If I change my habits to accommodate my medications it will probably help me.	1	2	3	4	5
28. My medicine makes me feel better.	1	2	3	4	5
29. I believe that taking care of infections will help me feel better.	1	2	3	4	5
30. The thought of having to cope with being ill puts me off my drugs,	1	2	3	4	5
31. Hearing about nasty side-effects associated with antiretroviral therapy reduces my incentive to take it.	1	2	3	4	5
32. Friends of mine have become ill while taking antiretroviral therapy.	1	2	3	4	5
33. Taking my medications interferes with my normal daily activities.	1	2	3	4	5
34. My HIV is well controlled	1	2	3	4	5
35. I eat a good diet and look after myself so I am unlikely to get ill.	1	2	3	4	5
36. The chances I might develop a new HIV related infection are pretty high.	1	2	3	4	5
37. My chances of developing AIDS are low.	1	2	3	4	5
38. I expect to be free of HIV related infections in the future.	1	2	3	4	5
39. Others are more likely to develop AIDS before I do.	1	2	3	4	5
40. No matter what I do, there's a good chance of developing a new HIV related infection.	1	2	3	4	5
41. My body will fight off new HIV related infections in the future.	1	2	3	4	5
42. I am a very resilient person and will fight against becoming ill.	1	2	3	4	5
43. They will find a cure before I ever develop AIDS.	1	2	3	4	5
44. I am generally a lucky person and therefore feel that good health will be on my side.	1	2	3	4	5

45. HIV can be a serious disease if you don't control it.	1	2	3	4	5
46. My HIV will have a bad effect on my future health.	1	2	3	4	5
47. My HIV will cause me to be sick a lot	1	2	3	4	5
48. There are many diseases more severe than HIV.	1	2	3	4	5
49. HIV is not as bad as people say.	1	2	3	4	5
50. HIV is a terrible disease.	1	2	3	4	5
51. HIV is just another chronic illness.	1	2	3	4	5
52. AIDS is a terminal illness.	1	2	3	4	5
53. AIDS can be overcome just like any other illness.	1	2	3	4	5
54. There is little hope for people with HIV.	1	2	3	4	5
55. The risk of death due to AIDS is high.	1	2	3	4	5
56. My HIV is no problem to me as long as I feel alright.	1	2	3	4	5
57. I believe I will always need my HIV medications.	1	2	3	4	5
58. Taking care of infections is an important part of treatment of my HIV.	1	2	3	4	5
59. My doctor tells me I should take antiretroviral therapy.	1	2	3	4	5
60. I want to do what my doctor thinks I should do about antiretroviral therapy.	1	2	3	4	5
61. Members of my immediate family think I should follow my treatment plan.	1	2	3	4	5
62. I want to do what my immediate family think I should do about my treatment plan.	1	2	3	4	5
63. My close friends think I should follow my treatment plan.	1	2	3	4	5
64. My friends have advised me to start taking antiretroviral therapy.	1	2	3	4	5

65. I want to do what my close friends think I should do about my treatment plan.	1	2	3	4	5
66. My partner thinks I should follow my treatment plan.	1	2	3	4	5
67. I want to do what my partner thinks I should do about my treatment plan.	1	2	3	4	5
68. My relatives think I should follow my treatment plan.	1	2	3	4	5
69. I want to do what my relatives think I should do about my treatment plan.	1	2	3	4	5
70. I have made a commitment to follow my treatment plan.	1	2	3	4	5
71. My plans do not include following my treatment regimen.	1	2	3	4	5
72. I intend to follow my my treatment plan	1	2	3	4	5
73. I have no intention of following my treatment plan	1	2	3	4	5
74. I intend to take my medications at the correct time.	1	2	3	4	5
75. I intend to take my medications in the correct doses.	1	2	3	4	5
76. I intend to follow the special instructions for my medications.	1	2	3	4	5
77. Lots of things get in the way of following my treatment plan.	1	2	3	4	5
78. I need more assistance to follow my treatment plan.	1	2	3	4	5
79. I get the help I need to carry out my treatment plan.	1	2	3	4	5
80. Reading good reports about antiretroviral therapy would encourage me to take it.	1	2	3	4	5
81. Seeing some of my friends who are not on antiretroviral therapy become very ill would prompt me to take it .	1	2	3	4	5
82. Starting antiretroviral therapy makes me feel an AIDS diagnosis is pending.	1	2	3	4	5

83. If I am taking antiretroviral therapy now it will cease to be effective when my body really needs help.	1	2	3	4	5
84. A large amount of weight loss would make me likely to consider starting antiretroviral therapy.	1	2	3	4	5
85. Whilst my body remains symptom free I should avoid taking antiretroviral therapy.	1	2	3	4	5
86. It has been difficult to take my medications as prescribed.	1	2	3	4	5
87. I cannot understand what the doctor told me about my medications.	1	2	3	4	5
88. I would have to change too many habits to take my medications.	1	2	3	4	5
89. I am able to deal with any problems in following my treatment plan.	1	2	3	4	5
90. Taking care of infections is too difficult for me.	1	2	3	4	5
91. I believe I can manage my HIV.	1	2	3	4	5
92. I can take my medication as prescribed.	1	2	3	4	5
93. I am able to take my medicine as often as the doctor prescribes it.	1	2	3	4	5
94. If I am confused about taking my medications I am comfortable asking my physician to help me.	1	2	3	4	5
95. I have no control over HIV.	1	2	3	4	5
96. I can remember to take my medications.	1	2	3	4	5
97. I know how to reach the clinic if I need more medications.	1	2	3	4	5
98. If I have side-effects from my medicine, I am able to have it changed or adjusted.	1	2	3	4	5
99. If I take my medicines I feel I am doing something to fight HIV.	1	2	3	4	5
100. If I run out of my medicines I wait until my next appointment to get refills	1	2	3	4	5
101. I am comfortable carrying my medicines with me if I go out.	1	2	3	4	5

102. My HIV would be worse if I did nothing about it.	1	2	3	4	5
103. I am able to take my medications at the correct time.	1	2	3	4	5
104. I am able to take my medications in the correct doses.	1	2	3	4	5
105. I am able to follow the special instructions for my medications	1	2	3	4	5
106. I am able to change my habits to accommodate my medications.	1	2	3	4	5

Is there anything else about your medications which you think is important which you would like to tell us?

Thank you for taking the time to complete this questionnaire